Global Conference on Rethinking Care
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“Rethinking Care” from Different Perspectives

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Introduction

Rethinking Care from Different Perspectives

According to estimates of World Health Organization, there are almost 500 million persons with disabilities in the world, more than 80% of whom live in rural areas and urban slums in the developing countries. For a vast majority of them, disability is still closely linked with the vicious circle of poverty, illiteracy and lack of services. The existing services, grossly insufficient in developing countries, have long been dominated by "care institutions", where children and adults with disability may be provided specialized services, segregated from families and communities. Two extreme examples of institutionalised care are persons with disability due to leprosy and mental illness.

> *..the institutions (were) getting larger and more distant from the city and so a whole different world was created, which was separate from the community, and even more so, from the family. The result was that the children, youths or old aged didn't have the right to be a part of the family and the community. (de Zaldo, p. 53)*

> *..the stigma associated with leprosy and the accompanying social isolation will only be eliminated when those who have experienced this disease have regained the identity, self-confidence and dignity..(Gopal, p. 44)*

The Global conference on Rethinking Care is an opportunity for disabled persons to contribute to the definition of policy issues related to health care and social support. It will thematically take as its starting point the first four of the *UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities*: awareness-raising, medical care, rehabilitation and support services.

> *..the right to life, dignity and freedom should be the fundamental principle underpinning all policies and practices concerning health and social care. (R. Hurst, p.39)*

This document is a collection of papers, presenting **Different Perspectives** on the issue of Rethinking Care, from the point of view of disabled academics and activists, their family members, as well as, from the point of view of professionals involved in care. The aim of this document is to stimulate reflections and dialogue among different actors involved in care. This document is composed of a *back-ground paper* for the Conference prepared by *Colin Barnes*. The paper written by *Vic Finkelstein* was sent to other contributors included in this collection, as a model.

A review of the way disability, rehabilitation, support and care have been conceptualised and organized in the past is needed because of changing context. The most important social change, especially over the second half of last century has been linked to gradual strengthening of *voices and views of persons with disabilities.*

> *.. the social experience of disabled people is singular, and that this uniqueness can provide extraordinary insight into the transformation of "care" as this*

> *migrated from the community into institutional settings and then back again. (Finkelstein, p. 5)*

The second half of twentieth century has seen the coming together of disabled persons, their sharing of experiences and the creation of their organizations, especially in developed countries. The development of social model of disability has identified the role of social barriers in limiting the choices and quality of life for persons with disability. At the same time, even in developed countries, the increasing costs of managing "Care Institutions", has promoted a return to community care services, still guided by the spirit of care institutions. At the same time development of community-based rehabilitation (CBR) programmes in developing countries have shown that CBR approach can be an instrument for empowerment for disabled people and their family members.

> *A growing number of people talk about not being able to use community mental health services when they need them, because there aren't enough services to go around, or because the services are too controlling, or because the assistance they provide isn't what people want. (Hagan, 29)*

> *..centre-based services, which focused primarily on medical rehabilitation and segregated education do not include or meet the needs of poor urban persons with disabilities...financial and skill resources should be directed towards community-based structures that demonstrate that they effectively reach poor people. (Venkatesh, p. 26)*

Health care professionals including specialists and nursing personnel have started to take note of the opinions expressed by disabled persons and their organizations. Some of them have tried to reconsider the role of traditional way of providing rehabilitation services, against the context of the social model of disability.

> *As persons with disabilities participate in the new world order, we can expect challenges to old models. (Salcido, p. 58)*

> *To promote positive change we must challenge old ways of thinking among nurses and introduce new models of care that encourage persons with disabilities to empower themselves. This movement requires no less than re-thinking nursing care for persons with disabilities across the globe. (Hossouneh-Phillips & Curry, p. 65)*

Organizations of disabled persons (DPOs) in developing countries point out the need for political will in ensuring equity in distribution of resources and underline the need for creating wider alliances between persons with disability and other poor and marginalised population groups in the new paradigm of care. These DPOs also point out the need of reaching disabled persons in poor and rural areas, with special attention towards girls and women with disability.

> *Disability and poverty must be addressed together. Whatever the situation, the additional costs of disability make the families poorer...the principle of inclusion means that persons with disabilities and non-disabled people have equal opportunities.. (Venkatesh, p. 25)*

RE-THINKING CARE IN A SOCIETY PROVIDING EQUAL OPPORTUNITIES FOR ALL, *Vic Finkelstein*

Introduction

This paper is concerned with 'community care'. I have not, however, set out to analyse the legal and structural components of 'community care'. Nor have I examined how well or how poorly community care policies are implemented. The paper does not look at or present research on this topic. I do not refer to and depend upon data from surveys or literature reviews. I have not taken my starting point from critical reviews or theoretical publications on community care, although, I would maintain, the content of this discussion is informed by such readings. Most importantly, it is not a purpose of this paper to set out and argue for a detailed solution or approach to community care. I offer no simple formula for addressing what is increasingly acknowledged as an international problem in implementing an appropriate level of care services in the community for those who may need such assistance.

Having said what this paper is not about I need to make clear what is intended. I have been asked by the World Health Organisation to prepare a discussion document that raises questions, stimulates critical thought, challenges assumptions and encourages informed deliberation about the nature and provision of 'community care'. The background to this invitation is a central acknowledgement: *whilst in principle provision* of *community care has become an internationally accepted goal, problems in implementation have persistently undermined realisation* of *this aim.*

In addressing this issue I should emphasise that my argument has been shaped by two prevailing influences in my own development: Firstly, I have been concerned and actively involved with a wide range of disability issues for over forty years. During this period I have participated in the establishment of 'disability studies' as an academic subject at university level. I have taught a very broad range of lay and professional workers in the field as well as students simply interested in the subject as part of their own personal development. I have carried out research concerned with service delivery and policy development, actively engaged with other disabled people in setting up and maintaining organisations of disabled people, and written and presented papers which challenge hitherto unquestioned assumptions about the nature of disability and concerns of disabled people. I do not claim that this extensive 'disability' experience, when focused on community care, is a qualification for determining the access needs of all groups who may use the 'caring' services. I do believe, however, that the social experience of disabled people is singular, and that this uniqueness can provide extraordinary insight into the transformation of 'care' as this migrated from the community into institutional settings and then back again.

Secondly, my understanding and analysis of community care from the experience of the disability field has been formed within the confines of British policy and provision. This has had a rather patchy (often described as a 'piecemeal') history since the 1960s and I make no claims about this being a good starting point for the development of an international consensus on what community care should or should not be about. As long as community care is viewed in economic, managerial, professional and technical terms the cultural component of service provision and service utilisation tends to be neglected and this, in its own right, will undermine the best of policies. In this respect different national traditions need to be addressed in specific detail whatever global proposals are made for the incorporation of cultural issues in the development of community care. The British experience should be viewed as just one of the cultural range of approaches that are currently addressing the subject of 'care in the community'.

Where to start?

In general, problems in the delivery of community care service are most frequently attributed to insufficient funding, inadequate planning and preparation time prior to implementing the service, and the absence of staff training or the training provided is inappropriate for the inter-disciplinary teamwork that is required for an effective service. Since the emergence of community care proposals in the 1960s these concerns have been intensively raised and discussed. Solutions, however, have on the whole maintained an attachment to the doctrine of delivering 'care' to client groups according to assessed needs. In other words solutions, from the technical {such as seeking to improve the management of services, improve the assessment of needs to ensure resources are not wasted, etc.), to the more radical {such as shifting from a medical model of community care to a social model of neighbourhood care) have not doubted the veracity of providing resources for services to those who are deemed to have special needs. In this respect there are two general presumptions made about community care which are rarely questioned: firstly, that community care services can assist 'people in need' to attain a greater degree of independence than otherwise might be possible for them if left entirely to their own resources, and secondly, that community care services can address the special needs of 'vulnerable groups'. I believe that reliance on these assumptions is one of the reasons why problems in community care are difficult to resolve.

In many respects, it seems to me, the absence of doubts about the value of community care corresponds with the absence of incisive questions about the legitimacy of addressing assumed independence needs of vulnerable groups. In any natural science a 30 year history of problems with a particular approach would certainly raise questions about the veracity of that approach. This seems to be a good starting principle for an examination into the problems of implementing community care services. With this in mind a return to the beginning of the lengthy historical process which eventually resulted in the current promotion of community care policies seems to be a sensible starting point. Three stages are raised in my mind when community care is looked at in this way:

Firstly, with 'disability' as the working example, prior to the development of residential, institutional and professional approaches to services for disabled people whatever help or interventions were on offer were provided in the community. Disabled people, their supportive family and friends had to be self-reliant. In these circumstances there would have been two concerns that had to be dealt with - 'caring' for those deemed unable to manage and 'supporting' those who can manage with assistance. Thus, in its origins, interventions directed at ameliorating the home conditions of disabled people involved an undifferentiated mixture of 'care' and 'support' provided by 'lay' helpers.

Secondly, following the population migration from the rural to urban areas as industrialisation developed and families faced new stresses their ability to provide care and support became increasingly difficult to sustain. Disabled people then became more reliant upon help from outside the family if beggary was to be avoided . This would apply to those most severely impaired and rather more dependent upon care than support. In time, then, as social affluence came with industrial development non-family interventions provided by the state targeted on the more urgent need for the provision of care. In these circumstances interventions became progressively professionalised around the perceived needs of those most liable to be displaced from the family. Care, then came to characterise and define the health and welfare approach to interventions directed at disabled people.

Thirdly, as the welfare state fragmented and its ability to provide care for a growing population of disabled people became more problematic pressure increased for interventions to be provided in the community .But during its lengthy incubation in exile from the community 'care' had become the dominant approach to intervention in the lives of disabled people. Thus on returning interventions back into the community it has taken the form of care in the community. Each of these stages can be considered in more detail.

Independent Self-Reliance

In the absence of *State health and welfare provision* the advent of a child born with a defect, or the appearance of an impairment due to illness or accident later in life, would present a family with additional concerns alongside the 'normal' pursuit of food, clothing and shelter. Most immediately this would entail the survival of the person with the impairment and consequently the need to solicit medical intervention. The intention of inviting such an intervention, into the home environment, would be to enable the removal of any physical impediment which threatened the person's endurance. The emphasis would have been on 'cure'. Once this immediate danger had been removed further medical expertise could be canvassed for advice and possible additional attention on the physical defect because of its known long-term life-threatening implications. The emphasis in these circumstances would remain focused on the removal of the defect, or at least reducing its severity. That is, the most immediate family judgements in the home would be driven by the need to find a cure for the presenting impairment and this would surely be followed by decisions about moving as much as possible in that direction.

Thinking about impairment and developing an awareness about its implications during the earliest active stage of intervention, then, would be agitated by goals directed at obtaining a cure. 'Impairment' , 'cure' and 'medical treatment' in this context constitute a tight *primary configuration of relationships* which are firmly attached to disabled people at a very basic level. Once the threat to survival has receded and the impairment attained a relative level of stability the functional autonomy of the individual is bound to become the family's secondary concern. However, the individual would now have a medical intrigue stamped onto their external, and hence, social identity. This identity, having been laid-down during the primary concern with curing the impairment, carries with it an automatic comparison with images of an idealised 'normality'. Henceforth the ability to complete 'normal' day-to-day activities of social life would be bound to trigger interpretations within this medical milieu. In this event the person with an abiding 'medical condition' (an Impairment) would be surveyed for the impact of their impairment on their ability to function in what are a secondary *configuration of* *relationships* in three scenarios: being able to function 'normally'; functioning with 'support'; or having a lasting dependency upon the provision of 'care'.

> (a) In the first scenario little social significance would be attached to the permanent medical condition. The loss of a finger, for example, might have no implications for independent assimilation into existing social relationships and facilities that are within the attainable circulation patterns of the individual. Curing this medical condition would not then become an important family priority. The impairment would be seen more as an 'ab*normal*' curiosity than as a condition which demands medical attention.
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> (b) In the second scenario the individual with an impairment may be able to function relatively autonomously within the existing environment (even though it has been created only by, and for, able-bodied people) provided an appropriate level of support is at hand. Asking a family member to make a cup of tea or requesting assistance to go to the toilet, for example, could be regarded as providing the kind of support in the home that would enable autonomy to be retained. The critical issue in the provision of 'support' is that the individual with the impairment asserts his or her own aspirations by deciding the goals to be attained while others help to accomplish these aims. This enables a level of autonomy to be achieved rather than independence or inclusion in an able-bodied world. In this scenario social significance would be attributed to the 'medical' impairment because others are called upon to provide assistance.

Although the magnitude of support requested would be covertly influenced by the accessibility of an environment designed for able-bodied living, it is *dependency upon others* that would be overtly 'suffered' by the supporting non-disabled members of the family. Consequently non-disabled people could easily come to regard social 'dependency' to be dormant behind every significant impairment. It is in this sense that every disabled person capable of managing their own lives with assistance could be considered 'vulnerable'. Any subsequent request by the family to external resources for additional help, then, would be attributed to the severity of the impairment and taken as evidence of disabled people's vulnerability and intrinsic social dependency.

The absence of reliable support outside the family setting would make the external able-bodied world largely inaccessible. In the period prior to State intervention perhaps the only active route that a person with a severe impairment could follow in gaining support to enable autonomy outside the home was by working hard at beggary .This would not negate the association of disabled people with 'vulnerability', however, because the disabled beggar would simply have changed status from being vulnerable as a disabled person to being vulnerable as a beggar. Indeed, in the public arena 'beggar' and 'cripple' would be almost synonymous terms (undoubtedly a major reason behind the modern erroneous presumption about the etymology of the word 'handicap'). Whatever else, the disabled beggar would not have entered the 'normal' world where autonomy is achieved through employment or marriage.

(c) In the third scenario the help that is offered is 'deliverer determined' rather than 'recipient requested'. It is in this respect that any universal acceptance of the right to autonomy (the right of individuals to determine the choices in their own lifestyle) can become profoundly undermined in relation to people with impairments. Family members may unthinkingly assume that they must be the decision-makers for their impaired relatives because the level of impairment predicates a level of support that simply cannot be provided in the home. When this happens 'support' starts to be replaced by 'care'. There are several reasons why this transformation may occur:

i) **Time**: The amount of time needed in order to support a person with an impairment may encroach too much on the helpers available time. For example, the female helper (invariably the wife or a daughter) could have a full programme of household duties involving cleaning, shopping and cooking. These activities have to be scheduled in relation to all members of the family. If the person with an impairment requests assistance at a time when the helper is about to leave for the market the helper may refuse because the sought-after purchase at the market may not be available at a later shopping time. A decision has to be made. If the request for assistance takes priority then this can have an impact on all members of the family who will forgo access to the intended market purchase (the menu for a meal may have to be changed). Certainly, the pressure would be on the helper to provide the assistance as swiftly as possible *and in a manner that suits the deliverer of help* rather than follow a slower course of action requested by the person with an impairment.

In circumstances where the absence of support at a requested time can exacerbate the home environment for all family members (eg. incontinence) the deliverer of help may insist on an action not requested by the person with an impairment (eg. place the disabled person on a toilet before leaving for the market). It is easy to see how limitations on available family time can lead to the imposition of practices on the person with an impairment (ie. others make decisions for that person) so that possibilities of family 'support' become eroded and increasingly replaced with 'care' regimes. Here is another example: the person with cerebral palsy who eats slowly and spills food at meal times may be fed by others rather than allowed to organise their own pace of eating because otherwise meal-times become too invasive in the family's time-table and after-meal cleaning becomes too time-demanding.

ii) **Finance**: The financial status of the family will also affect the pace of transformation from 'support' to 'care' within a family. Financial resources to purchase or have made appropriate aids or equipment, such as an individually designed spoon so that the person with cerebral palsy can feed her or himself more efficiently (in terms of the families needs!), could influence *if*, *when* and *how* the person with an impairment is to be cared for by being fed. The state of technological development in society, of course, will provide the permissible context for this development. Improvement in community sanitation and medical expertise could result in more people with severe impairments surviving in families that are less able to support them without a concomitant improvement in, and access to, appropriate aids and equipment. The extent of the hiatus between the presence of increasing impairment and new technology. enabling autonomy would, I believe, have a significant impact on any emergent demand for the social provision of 'care'. Conversely, the more affluent family may buy-in workers to care for their disabled members, rather than purchase any aids or equipment that would facilitate autonomy.

iii) **Attitudes**: Another consideration in how far a family, or individual helpers in the family, are prepared to go in providing 'support' before 'care' becomes the behavioural alternative, is the perceived *attractiveness* of the task to be carried out with the disabled person. Helping a disabled person dress, brush their teeth or bath may be regarded as unpleasant tasks and carried out to a minimum standard and as infrequently as possible. If over a period of time it is the helper who makes most of the decisions about when and how these tasks are to be carried out then what started as supporting the desires of the disabled person may turn into 'caring for' that individual.

Obviously those who are engaged in helping disabled people may hold any combination of attitudes towards the help that they feel obliged to provide. These attitudes will be seen in the perfunctory or elaborate way that helping support and/or care are actually provided. Being seen in public pushing a person in a wheelchair, for example, may be regarded by the non-disabled person as a particularly unpleasant, embarrassing or shameful experience. In these circumstances the prospective helper may select more secluded environments to take the person in a wheelchair or try and get other members of the family to carry out the disliked task. In such circumstances it is the helper who starts to become the 'majority shareholder' in the decision-making process and the degree of support offered is eroded by extending the bias towards care.

The thesis presented in this section is that prior to the development of substantial state intervention in the lives of disabled people families provided an unrecognised composite of support and care. It is my contention that these two forms of help were undifferentiated in the minds and actions of those providing assistance and that in the short and long term bustle of family life there would be moments as well as periods of time when either of support or care would predominate. It seems to me, however, that when the care form of assistance assumes supremacy over a period of time in the family setting and the fluid movement of help between support and care becomes more difficult to sustain, then having the disabled person taken into care may reluctantly be seen as the only option.

Collective Institutional Intervention

The care approach to intervention, then, would appear to have started its journey towards an independent, distinctive and formal career only when informal assistance, comprising an undifferentiated mix of support and care, began to break apart. Before 'care' could be repackaged as a service delivered by health and welfare professionals, however, it not only had to be separated from family 'support' but the latter form of assistance had to become culturally subjugated. My contention here is that in the face of limited time, insufficient finances and changing attitudes families found it increasingly difficult to provide an appropriate level of support. This resulted in a pressing demand for publicly available care services. Using such a service, of course, would immediately reduce the burden that non-disabled people might feel in assisting disabled members of the family. This would reinforce its attraction as a universal form of assistance. As a result the importance of developing and providing disabled people with support was devalued and the demand for care services began to dominate both professional and public presumptions of what is an appropriate form of assistance for disabled people.

Disabled people too would seek access to care services when the prevailing experience of the support provided in the home is perceived as 'deliverer determined'. This is because the provision of 'objective' efficient care might be considered less stressful than being dependent upon the intrusion of others when assistance is reluctantly provided or coloured by strong emotional and personal ties (eg. in dominating, over-protective or possessive families).

Disabled people placed into the diverse range of institutions providing a variety of care would be joining other population groups who have been removed from the community - such as the homeless and beggars, those taken from their homes because of illness, or when abuse in the family is reported. Staff working with these groups in the medley of institutional settings isolated from the community, then, would have their experience of disability coloured by those most dependent upon assistance and most vulnerable to abuse. In this context it is easy to see how disability could then come to be equated with dependency and vulnerability.

The grand historical trend then, I would argue, was for 'support' to be disowned and replaced by 'care'. Consequently, 'support' as a form of assistance for disabled people never acquired formal recognition and never became the property of any specific group of researchers or service providers. With the support approach receding into the background 'care' entered the public health and welfare domain as the most conspicuous and indispensable component of services for disabled people alongside that of medical intervention. The bipolar 'cure' or 'care' approach to disability, and all imputed 'vulnerable' groups, then, became the warp and weft. for the fabric making up the national health and welfare service.

It should be noted, however, that support in the family certainly never completely disappeared, although this form of assistance was probably increasingly interpreted in terms of 'caring for the disabled'. I shall argue later that in the 1970s the 'support' form of help, in the guise of 'independent living', began to re-emerge as the newly formed organisations **of** disabled people developed their own, and spontaneous, alternative to 'care'.

The distillation of 'care' out of the community into the hands of specialist service providers was undoubtedly a long, complex and inexact process which began in the mid-nineteenth century .Its development followed fluctuations in the national economy, commercial demands for access to workers, changes in the fortune of political parties and the ability of parents and disabled people themselves to exercise pressure on governments for change. Given this diversity it is only practical in this paper to indicate the possible key elements which now appear to constitute the essence of professionalised 'care'.

As already mentioned, the disabled recipients of care are in the first instance a very select group of people. These will be the people who have been identified as unable to cope with the 'normal' activities of daily life because of the severity of their physical or mental impairments. While in some cases it might be readily agreed that individuals are taken into care because *their families* cannot manage, on the whole the cause of the difficulty would be attributed to the problem of accommodating a *person with an impairment* in a particular household. This provides us with two fundamental components in the construction of 'care' as a definable service: firstly, that disability creates, causes or is a problem; and secondly, that although this problem belongs to or is a part of each individual disabled person, its resolution requires the active intervention of (non-disabled) others.

The most basic way of dealing with the problem *created by disability* (as discussed here) is custodial - taking the disabled person into care. Once within an institutional sanctuary those providing assistance could then concentrate on ensuring that the elementary conditions for sustaining life were delivered. Caring for the 'unfortunate' in a residential institutional setting has been extensively analysed. However, this has tended to focus on the nature of the institution's caring regime and its impact on the inmates. The converse, that is the impact of assumptions about 'disability' on the evolution of institutional care, has been neglected simply because the validity of *caring for the disabled* has not been questioned. Thus, in the isolation of the institution, the difficulties faced by disabled people could be addressed *as if these were quite independent of any relationship to the real physical and social world* and the construction of care in this setting could incorporate unchallenged notions of disabled people as incapable of autonomous social functioning. My contention here is that care, as a systematic approach to intervention in the lives of disabled people, developed in isolation from the community and that this isolation was an essential ingredient for the foundation of the modern caring professions and the knowledge base underpinning care policies.

Within the secluded environment of the residential institution, hospital or rehabilitation centre (as these developed over time) disabled people and other dependent population groups placed in these localities are a captive community where the *culture of care* can mature with little of the uncertainties that accompany 'recipient requested' support interventions. Managing the institution and managing patients or residents requires a level of planning that can only become effective with the identification of a number of matters that *must* be dealt with. These matters are wide-ranging and include such concerns as when, and what, materials should be purchased for running and maintaining the estate, at what times should staff be employed, how should the budget be determined, etc. Similar management issues would have to be resolved in maintaining the welfare of the inmates of the institution (the residents or patients), such as when, and what, food is appropriate for their consumption, at what times should they be allowed or assisted to or from different parts of the building, how should resources required by the institution's users be calculated and budgeted, etc.

Solutions to these compelling administrative problems require well-defined itemised inventories. Leaving aside management issues related to the building and its maintenance the question for staff working directly with patients or residents is what is the best administrative means for constructing an inventory of those matters related to the welfare of the residents so that the appropriate resources can be made available? In my opinion, during the lengthy period in which the 'care' approach to interventions matured in isolation from direct contact with the community , the identification of *needs* was to become the pre-eminent tool in composing an inventory of an individual's problems requiring physical and human resources. The task of the *expert* carer (as the work of staff in these places of care were transformed into professions) was to carry out the needs assessment and then administer to the resource provision (sanctioned by legislation).

In this section I have argued that a 'culture of care' evolved when the support and care forms of assistance were separated, the 'care' component was isolated from the community and then transformed into a professional service. The key features of this culture may be summarised as:

- care and support forms of assistance are separated
- care becomes a specialism during its incubation and while isolated from the community; support declines in significance
- problems in social functioning are attributed to personal defects (impairments)
- impairment is thought to result in disabled people becoming dependent on designated service providers (the care professions) who are socially responsible for dealing with vulnerable groups
- the identification of needs becomes a central focus for determining the allocation of resources
- 'medical', 'administrative' and 'individual' models of disability add variation to the final shape of the culture of care (with the medical profession exercising overall hegemony)
- the culture of care is deliverer determined (ie. no service users contributed to its development or the formulation of the service details which it encompasses, standards are set by the care professions for themselves by themselves)
- in the culture of care the real client is not the recipient of the assistance because funding for the service does not originate with the users.

Regulated Community Care

A builder or designer can always conceive of ways to improve a house. The only constraint on removing a wall, altering a room, adding a floor or extending the garden are the financial resources and amount of time available to make the changes. It is in the nature of being a good professional to constantly seek creative ways of applying one's expertise. This has certainly been true of the caring professions. Working with a captive and dependent group of people with the objective of bettering their health and welfare is an open invitation for the dissection of patients or clients into a plethora of problem areas where one's skills can be applied and improved. With the analysis and assessment of each problem area comes an infinite expansion in the development and regulation of professional expertise and resource requirements. The creation of large custodial and remedial institutions (especially the asylums, and later hospitals for the 'mentally ill', 'mentally handicapped' and 'chronic sick') provided an ideal environment for collecting together 'vulnerable' groups of people where formalised approaches to intervention had the maximum opportunity for the caring culture to germinate.

While this growth originated in large custodial institutions it was the creation of a National Health Service that sanctioned the massive professionalisation of care. With this came a new breed of worker, nurtured in the culture of care, and dedicated to remedying the health and welfare problems of their patients (later according to the fashions of the time also referred to as clients and service users, etc.). The growing number of 'practitioners' in the caring services precipitated a demand for more efficient therapy, training and courses focused on vulnerable groups, and finally qualifications and career structures with higher salary scales. As the expertise of each class of carer became more identifiable, and professionalised, *faith* in the singular importance of 'care' turned into *fact.* The transformation of occupational therapy from its beginnings as a way of filling the time of convalescent (and chronically ill) patients to a planned schedule of functional activities specifically designed to achieve physical and mental goals exemplifies the motive logic of the 'care' culture. No one questioned whether a profession, which models the correct way of doing things for others, should legitimately originate from deliverer determined practice involving taking care of people who are removed from the community. Nevertheless, the demand for occupational therapists seems endless, particularly with the advent of community care policies. In the context of 'care' there is a logic in the growth of the professions alongside a persistent shortfall in the numbers of practitioners.

Considered from the perspective of disabled people the institutionalisation of 'care' has been a mixed blessing. As the boundary between support and care crystallised care workers were able to focus attention on the identification of physical and mental deficits where aids, environmental adaptations and equipment can assist individuals achieve greater approximation to 'normal' functioning. However, with each improvement in independent functioning disabled people gained opportunities to formulate and exercise their own judgements about forms of assistance appropriate for themselves and who ought to have the right to determine the nature and structure of the helping service. The expanding professionalisation of care services creates its own ambiguities in the minds of the 'users'. Experts who broaden one's experience and vision of what is possible are valued while at the same time the intrusive attention of these workers inevitably raises anxiety about their continuing influence over one's lifestyle. The institutionalisation of care not only concentrates attention on the individual's deficits, or problems, but in so doing identifies and reinforces the boundary which separates disabled people's right to specialised help from that of the 'normal' citizenship right to public utilities. In the 'care' culture disabled people's rights are detached from basic human rights; such as the right to choose, the right to privacy and, most important for an active citizenship, the right to have a defining influence on the nature and structure of the supportive services that one is entitled to use. In the 'culture of care' it is a self-evident fact that disabled people are *vulnerable*, *special* and *dependent;* others therefore make the decisions.

In my view a fundamental internal defect in the collective institutional provision of 'care' eventually made its continuing expansion isolated from the community unsustainable. In the long run this defect appears to have resulted in the following irresolute problems:

- 'care' generates a bottomless demand for resources managed by an increasing population of service providers targeting on finer and finer subdivisions of people's bodies and lives;
- people who are in various forms of care isolated from the community where interventions are aimed at maximising functional 'normality' and then return to their own homes are often confronted by disabling environments that the development of personal skills cannot resolve;
- in the late 1960s there was a sudden and rapid growth in dissatisfaction with the cumulative experience of incessant 'assessments' which nevertheless still left gaps in provision and at the same time left administrative control over disabled people's citizenship rights intact;
- the growth in provision of 'care' services had little effect on disabled people's access to mainstream national institutions and public utilities;

- despite any commitment to independence goals growing provision of 'care' was often experienced as increasing passive dependency upon experts.

With increasing government, public and user awareness of the unresolvable problems resulting from the provision of care in isolation from the community the case for a shift to community based services became overwhelming. That these problems may have arisen as a consequence of separating 'care' from 'support' and then institutionalising the former while stifling the latter did not feature in the debate about developing a more effective national approach to the provision of services for 'vulnerable' groups. The caring ethic and attendant culture, then, began to migrate back into the community where it clashed, collaborated or merged with existing social and welfare service suppositions.

During its exile from the home environment of users (the so-called vulnerable groups, especially disabled and older people) the philosophy of 'care' had become the property of very influential professions. They were in a particularly advantageous position to discuss, research and promote their approach to intervention because there was no real alternative to the care culture. As far as disabled people were concerned one either cured or cared for this problem group. With the introduction of community care legislation, as the health and welfare services began to fragment under the stress of maturing unworkable policies, the caring professions faced no rivals in securing cultural domination over the new community based services.

The implementation of community care policies, however, immediately ran into three main intractable problems:

- The recipients of the new community based approach to services were often already familiar with the power of deliverer determined 'care' in defining what are appropriate physical and mental standards and consequently wary of even greater control over their lifestyles in the community.
- Whatever the rhetoric an important reason for shifting services into the community was the State's need to limit or even reduce the ever expanding costs of 'care'. Since the crises in institutionalised care was already exacerbated by shortages' in staffing and resources, maintaining or cutting funding could only increase the problem of implementing care in the community. As a result the development of community care almost immediately triggered complaints about inadequate funding and personnel. With 'care' at its heart community care was not proving to be any cheaper than the system it was meant to replace. Indeed, with staff leaving because of poor pay and working conditions the ability to attract and maintain adequate numbers of carers now seems even less viable. Taking 'vulnerable' people into custodial care is once again threatening to return (especially in relation to 'mental illness').
- In the 1960s and '70s the fragmenting health and welfare services strengthened people's wish for an improved supportive service which could provide assistance in realising lifestyle aspirations, rather than having one's needs cared for. This galvanised disabled people into advocating and eventually setting up their own support systems. These have generally been located in the offices of voluntary organisations or Centres for Integrated Living (also referred to as Centres for Independent Living). Not only do these services represent the embryonic return of 'support' in the community but also a return to the original tension between the care

and support components of help. With full backing from the State, experts, families under stress, the vastly expanding numbers of unpaid carers and the prevailing culture of care, community care is asserting its hegemony over all services in the community. However, disabled people are now championing their citizenship rights in strong self-help organisations which are much clearer about the kind of assistance and mainstream utilities that are wanted. 'Care', as currently conceived, appears to be universally disliked by service users. This tension is certain to increase, making the new community service, with its skewed emphasis on 'care', unworkable.

To these problems we can add an entirely new set of challenges to the concept of community care. Amongst the most obvious are:

- The drive for efficiency, which was integral to moving 'care' back into the community, has generated a whole new battery of needs assessments. These are far more elaborate and intensive, creating a new round of tension between deliverer determined and recipient requested notions of appropriate resource allocation. Successful living in the community as an integrated citizen demands access to support systems which can assist in the attainment of unpredictable aspirations. Indeed, 'unpredictability' in deciding what is important for one's own lifestyle can be regarded as an essential component of being human. This is a right (even if substantially absent for very many people) that is expected in the mainstream community and necessitates a different approach to reckoning an individual's objectives from that of the needs assessment procedures prescribed in the culture of care.
- Providing assistance when entering the home of a 'client' is not at all the same as delivering a service to a person isolated from the community " Within one's own home, no matter how one construes what is wanted or needed, the recipient of help has some idiosyncratic control over the identification of barriers to be addressed. While the carer, or the professional assessment, may identify a healthy or correct way of carrying out a task or arranging the home environment a disabled person in her or his own home, for example, may have different inclinations which will take precedence. Entering a client's home with prescriptions about the 'right' response to different types of impairment (guided by the medical model of disability) may well be experienced by the service users as oppressive.
- The power exercised by the caring professions in determining what is appropriate for 'vulnerable' people that is maintained by the boundary between special and mainstream services is not unchallenged in the community .Disabled people in the self-help organisations that they have created see themselves as part of a diverse society where 'special' and 'mainstream' services and utilities are not mediated by 'carers'. The growing demand for 'rights not charity' exemplifies a simmering conflict with the hegemony of 'care'.
- Being a citizen is an active exercise in identifying and realising one's comprehensive ambitions. Whatever the intention a holistic approach to community care, which is driven by idealised normal functioning, cannot actually facilitate such self-control because it is an exercise in patching together the historical division of disabled people's lives into professional concerns. The resulting boundary between different caring professions inhibits the active role that disabled people can play in defining and participating in assistive networks.

- The emergence of a 'disability culture' has set the stage for an alternative, and I believe we might say, holistic drama in which care in a society providing equal opportunities for all can be subjected to a thorough re-examination. Na"ive presumptions which underline the late 1990s growth in courses, training and qualifications in a one-sided approach to community care are bound to attract increasing hostility from service users as they explore the importance of 'support' in their own political campaigns for civil rights; academic courses and research; auditory, visual and performing arts; and self-help services.

In many respects the appearance of these endemic and new problems are not surprising. They are exactly what can be expected when 'support' is excised from the provision of assistance within mainstream society. In other words the return of 'care' into the community has highlighted the one-sided nature of professional assistance that was created when a boundary was erected between the original mix of care and support provided in the home's of disabled people and the provision of segregated care delivered by specialists. 'Care' cannot be mainstreamed (return into the community) without resurrecting the return and provision of' 'support'.

Faced with this problem professional carers have tried to fill the gap in service provision (the missing support) by increasingly engaging disabled people (and other 'vulnerable' groups) in the process of refining community care. In the first place there have been a number of determined consultative exercises in which disabled people were invited to make presentations at professional conferences and in professional journals. This has been followed by professional/user collaboration in research projects; such as the correspondence in views between providers and recipients on the effectiveness of service delivery. More recently, collaboration has led to 'consumer' participation in the training of caring professions (such as social work). The latter appears to be concerned with improving quality control in training and service delivery. However, in all these exercises the agenda is being set by the caring service providers; that is, the collaborative exercise is deliverer determined. 'Care', as a concept in practical intervention for specific 'vulnerable' social groups, is not questioned. Consequently, whatever the intention, the function of engaging users in service appraisal ends up being an exercise in providing legitimacy to a impoverished community care programme. The recipients of 'care' are now being asked to lend 'support' to both lay and professional carers! Perhaps in this context it is no accident that one of the rapidly growing areas of concern is the need for support networks to assist carers.

I believe the lesson emerging is that assisting disabled people (and other specific groups) in the community can only become viable when the concept of 'aspirational support' is addressed -that is, how to construct services which are in essence concerned with supporting disabled people realise their personal aspirations. This, it seems to me, requires an honest admission that community care cannot succeed because a key aspiration of care receivers is not to be a vassal of carers. This is more than not just wanting or needing 'care' but recognising that care and support {; need to be reconciled, repackaged and then *offered* to an informed citizenry who perceive the new form of social assistance as just one of the many mainstream utilities at service to the public. I am arguing, here, that the fundamental defect in the culture of care is that the conceiving boundary between care and support eventually gave birth to a boundary between providers and users.

Aspirational Support

Of course, the majority of disabled people, like most other 'vulnerable' groups, remain in the community where families provide an imperfect mixture of support and care. As I have suggested before, this is almost inevitably perceived within the framework of the dominant culture of care as involving a struggle to care for one's dependent family members. However changing circumstances, including the real gains facilitated by carers and economic affluence, as discussed earlier, provided an opportunity in the late 1960s for some disabled people to gain access to mainstream society and the social debates of the *time.* This afforded both the stimulation and opportunity for the *creation* of a new breed of self-help organisation which advocate full integration into mainstream society. Instead of accepting the prevailing view that their impoverished social circumstances is the product of personal physical and mental impairments their situation is now being attributed to disabling barriers created by a world designed for able-bodied living. Criticism of the medical model in other areas (such as health and midwifery) was applied to disability and the social model of disability was adopted as the framework for developing recipient requested support services.

The key feature of this development is that it is the aspirations of disabled people that is guiding the identification of disabling barriers that need to be removed, the resources that are required and the services that need to be put in place. In practice there is no separation between the political campaign for civil rights legislation and making resources available in a support system to assist people identify and realise - their lifestyle goals in a barrier-free society. This enables interventions to perceive individual idiosyncrasies within holistic concerns. 'Disability studies' and 'emancipatory research' are two areas wholly created by disabled people where the new paradigm is being developed.

Care in the community, however, with its deliverer determined orientation is still being pursued as if there has been no fundamental shift in the balance of evidence which demonstrates the unworkability of this one-sided approach to community based services. Indeed, where the community care philosophy has complete ascendancy, such as in academic institutions, disability studies is being absorbed into the care paradigm. Of course this effectively suppresses the emergent emphasis on the provision of support that disabled people are bound to champion. I have not the slightest doubt that in these circumstances service users will ultimately attack the academic veracity of the community care qualifications that are awarded.

On the ground, in the community, the fragmenting health and welfare services have opened a slot where disabled people have managed to start their own services guided by the social model of disability and, although perhaps often not recognised as such, where they are developing and implementing interventions based on the principle of 'support'. These are often referred to under the heading 'independent living', and the facilities as 'Centres for Independent Living' (CILs). This can be rather confusing because the term 'independence' is well-established in the language of 'care' and perhaps reflects the extent to which the culture of care has been absorbed into the consciousness of prevailing service users. The term 'integration' is also used to highlight disabled people's aspiration to integrate into mainstream society with the concomitant goal of integrating their own service ideas with enabling community based services. CILs, in this case, refers to 'Centres for Integrated Living'.

These developments are still at a very early stage and under considerable threat from economic constraints and a still strident advocacy of community care by non-disabled service providers. In essence, while community care remains an esoteric service independent of mainstream provision, organisations of disabled people have invested considerable and growing attention on mainstreaming their needs alongside society's diverse population groups and many faceted cultures. An important constituent of this development has been the creation of a disability culture challenging the hegemony of the caring culture. In my view the unfolding social model of disability not only needs to rediscover the importance of the long suppressed 'support' component of assistance located in the community but champion its rightful place, at the very least, as an equal contributor to the formation and transformation of the next generation of service interventions.

While, in many respects 'care' can be interpreted as irresolute support it would be incorrect, in my opinion, to regard the availability of care as having no relevance to disabled people, whatever their age. The real challenge in developing appropriate mainstream community services based upon equal opportunities for all, is winning over service users, providers and policy makers to the notion of disentangling appropriate skills located in the training and qualifications of the current caring professions together with the hitherto unknown and neglected skills that may be informed by a support paradigm and repackaging these into new community based professions. This model of provision has been called 'resource consultancy'. The new community worker (Resource Consultant) would need to be conversant with care and support skills which are at the service of aspirant citizens who face social and physical barriers in achieving their personal goals. This lifestyle orientation would be geared towards assisting people attain their personal goals and aspirations. The focus of any identification or assessment procedure would not be on the origin and meaning of an individual's deficits but making resources available for future goals. This could not be guided by any stereotype which sees disabled people in terms of pre-ordained dependent lifestyles.

Unravelling the care and support components of community based assistance and repackaging the exposed skills more appropriately according to the perspectives of the principal resource users could generate more profound opportunities for users to contribute truly innovative approaches to the services that they use. This could create a mutually healthy learning relationship between disabled people and service consultants.

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RE -THINKING CARE – VIEW FROM SOUTH, *B. Venkatesh*

> *“The hard reality is this: All cultures are still injected by the devastating ancient assumption that people with disabilities are not fully human. In too many nations, we are still beggars - outcasts, left to die in the streets. In others, we are segregated in prison like institutions or the back rooms of ghettos. There is no nation where we have completely equal access to the mainstream of culture. There are still countries where babies with disabilities are abandoned or simply killed. How many of our brothers and sisters with disabilities die each year by murder, suicide or denial of the basic necessities of life? Five million? Fifteen million? Twenty million? Nobody ever bothers to count. We count whales, elephants, tigers and spotted owls, and we protect them. For people with disabilities, we don’t even bother to count the dead!” - Justin Dart.*

Introduction : This paper examines:

- The situation of disabled people in India ;
- To what extent the social welfare policy has been able to address their needs;
- Similarity with other third world countries;
- The role of disabled people’s organization in policy development ;
- An experience of empowering disabled people at the grass roots.

Situation of disabled people in India

Since independence in 1947, the Indian population has grown from 350 millions to almost a billion. There is no record of the growth or fall of the disabled population in the last 53 years. The only time the census of disabled people was taken was in 1981, thanks to the International Year of the Disabled Persons. According to this census, 3.18 per cent of the population was estimated to be disabled.

One would have hoped the inclusion of disabled persons in national census would have become a matter of course. That was not to be. In the 1991 senses, disabled people were not included, however a national sample survey was taken.

Planning without census data: In the first three of the *five-year plans*, there was no separate resource allocation for disability. The resource allocation from the fourth to the eighth five-year plans are as follows:

Fourth plan	- 250 million Rupees*
Fifth plan	- 112 million Rupees
Sixth plan	- 250 million Rupees
Seventh plan	- 1,320 million Rupees
Eighth plan (currently running)	- 2,400 million Rupees

* Current exchange rate, 1 USD is equal to about 44 Indian Rupees

These resources are earmarked for schemes for scholarships, aids & appliances, grant in aid to NGOs providing services to disabled people, Transport concession, running educational, vocational training institutions and sheltered homes for disabled people. Four national centres; one for each of the four categories of disabilities were also set up to train professionals. A corporation was also set up to produce artificial limbs (ALIMCO), Artificial Limb Manufacturing Corporation of India. A legislation was passed in parliament in 1995, to protect the rights of disabled people and to promote their equal participation in national development.

Despite all these well meaning efforts, not even 5 per cent of India's disabled population has access to primary education. Although there is a reservation of 3 per cent in job opportunities for disabled people in the organized sector, only about a 100 thousand disabled people, out of seven million of employable age have found placements.

Considering the different activities, globally only 2 per cent of India's disabled population of about 30 million have benefited from these efforts.

What has Gone Wrong?: Nagu's Story

Lakshmiand Subbana are agricultural laborers earning no more than Rs.50 a day between them and that too when they have work. They have three children, one of whom is affected by polio. Nagraj, Nagu as he is called, had an attack of polio when he was three months old. Lakshmistill remembers the day when she went to the health clinic to get him immunised, but the health worker did not turn up. She was asked to come the following Wednesday, but she could not go as it would have meant loosing a day's wage. She often recalls that although her neighbour got her children immunised, one them was still afflicted by polio. She consoles herself by thinking that it is God's will that Nagu is lame.In search of a cure, they borrowed money from the landowner to perform religious rituals, to make pilgrimages and sought cure with traditional healers. They also lost many days of work. Their life got into the iron grip of the vicious cycle of debt.

Today Nagu their only son is 18 years. He sits by himself in front of the house and watches the world go by. Often you can find him gazing aimlessly. His parents and grandparents sometimes despair about Nagu's future and say, "its best that he were dead." It does not need much imagination to de-cipher the root cause of the situation of Nagu is poverty and all that goes with it - no access to information, inability to use information, poor quality health delivery to the poor, ignorance, exploitation and so on.

This story is similar to that of millions of disabled people in the world. More than 60 per cent of disabled people live in rural areas in India. It is reasonable to assume that 60 per cent of the 30 million disabled people in also live in Villages. Government of India reports estimate that 38 per cent of the people in India live below the poverty line; but independent studies estimate this figure at around 66 per cent. It stands to reason the disabled people and their families are part of these figures.

The following extracts from the new Internationalists helps established that the root cause of the situation of the disabled people is poverty:

Liberty, Equality And Disability - The Facts

Numbers

500 million people in the world are disabled - roughly one in ten.
300 million live in developing countries.
140 million are children.
160 million are women

Causes: Over100 million people are currently disabled as a result of malnutrition - that's one in five. Iron deficiency, anaemia and chronic pelvic infections are major causes of disability in women in poor countries. The latter is often caused by female circumcision - which affects at least 80 million young girls and women and teenage pregnancy.

A handful of green vegetables everyday would be enough to save the eyesight of 250,000 children who go blind every year because their diets lack Vitamin A.

Lack of iodine is the chief cause of preventable intellectual disability in the world. It is estimated that about 800 million are at risk. Mostly in Asia.

Poverty: Most people with spinal cord injuries in Third World countries die within two years of becoming disabled due to lack of facilities. In developing countries only one per cent of disabled people have access to any form of rehabilitation. 80 per cent of disabled people live in Asia and the Pacific but they receive just two percent of resources allocated to disabled people.

Education: In poor countries the vast majority of disabled children do not go to school and do not find a job.

Work: It is estimated that 80-90 per cent of all people labelled as 'mentally handicapped' are unemployed.

Gender: Disabled women are doubly disadvantaged. The figures in all categories are much worse. In the Philippines only 19 per cent of disabled women are employed and 95 per cent of those have to settle for very low wages. Only $35 per month, one third of the poverty threshold."

This situation is predicted to get worse between 1992 - 2025. The prediction is that while there is likely to be a 14 per cent drop in disability in industrialized countries, there is likely to be an increase of 47 per cent in disability in third world countries.
Policies and programmes for disabled people do not address the root causes of poverty. They, at best, aim to provide services to disabled people. Any policy that does not take into account the root causes of the situation of the disabled people but aims only to cater to the special need of disabled people will not change the situation of disabled people. The 50 years of the Indian experience bear testimony to this.

The way out

The chapter entitled " Social justice and the demographic transition: lessons from India's Kerala State" by John Ratcliffe in the book "Practicing Health For All by Morley, David - Oxford University Press" explains how the Indian State of Kerala, despite low per capita income, has dramatically reduced mortality and fertility through emphasizing equitable socio-economic and political development.

The development strategies and equity considerations that Kerala has used for this are summarized bellow: Early land reforms have helped to reduce inequalities in wealth and income. Another important factor is that Kerala has a high wage rate and land-less labourers enjoy a high bargaining power. Recent legislations have also acted further to reduce income inequalities in Kerala. A bill passed in 1974 was designed not only to provide security of employment to agricultural labourers (a first in India), but also better terms and conditions of work, including welfare (provident) and pension funds. Under this law employers contribute 5 per cent of the employee's wage, and the employee receives the money accrued at age 60. Employees who work in industry, services and government receive pensions upon retirement under provisions of earlier legislations.

Political power and participation are not concentrated among the few. The success of the CPI (Communist Party of India) movement has been rooted in its ability to organize lower class and caste peasants who were dissatisfied and frustrated by oppressive landtenure systems. Legislations in this state are not much different from the rest of India. The only difference being that labour laws are enforced rather than ignored. Implementation of the laws is effective on account of organizing people towards a better socio-political awareness.

Though not necessarily of a higher quality, utilization of health facilities is the highest here as compared to other states, due to the widespread understanding of both individual rights and access and political process Kerala spends only 12% of its educational budget on higher education as against 47% in other states. Female literacy in Kerala has increased enormously since 1950s. Increased educational levels also tend to be associated with increasing age at marriage for women. A recent study has found that 22 per cent of Kerala's women never marry, while the comparable figure for India as a whole is only 7 per cent.

Social mobility and the status of women have been significantly enhanced due to a weakened caste structure. Land reforms have provided millions of couples with the opportunity to invest in land rather than children as a long-term security investment. Wages have been increased, job security for the land-less has been legislated, and the need to rely upon children to fulfil welfare functions has thus been diminished. When the value of children as employable economic assets declines, so does fertility.

In terms of social and economic development strategies, Kerala's successes has been achieved not by the allocation of more resources, but rather through a more equitable distribution of existing resources, goods and services. And the distributive political economy that distinguishes Kerala so clearly from other states has also been largely responsible for mortality and fertility decline."

The impact of mortality and fertility decline on the incidents and prevalence on disability is worth studying. Generally the Physical Quality of Life Index, and the Basic Needs Approach, among other approaches are used to measure poverty. The status of health is also used to arrive at the prevalence an incident of disability. At best, for want of reliable data, one can only assume that the situation of disabled people including incidents and prevalence would be different for disabled people in Kerala State.

An Indian experience in empowering poor disabled people

The author of this paper has been responsible and actively involved in organizing disabled people in poor rural communities for the last 13 years. He has set up an NGO to do this in South India. Currently he is a trainer and a consultant to promote this approach to disability work in other parts of India and in other Third World Countries.

Recognising that fundamental change in the situation of the disabled people can be brought about only by disabled people themselves and that social action on disability should be a part and parcel of over all development of poverty issues, this work was initiated by the author. The strategy has been to influence existing NGOs in rural development to undertake organizational work of disabled people as part of their own programme. In order for NGOs to do this, systems and methods were developed in policy formulation, programme design, training staff in critical awareness on disability and to provide field support. Experience shows that NGOs are able to continue the work on their own after an intensive support period of about 2 years.

This strategy has enabled about 20 NGOs to undertake organizational work of disabled people in the villages where they are working. The NGOs procure the funding for this work as they do for their other programmes.

This initiative has enabled about 20,000 disabled people to organise themselves into Cross Disability Advocacy Groups. Parents, relatives or care givers represent disabled children and those who are severely disabled. These groups are village based. They not only take up issues concerning their membership pertaining to disability such as education, literacy, income generation, and aids and appliances, but also common village issues such as provision of safe drinking water, better roads, better public health service delivery etc. What is particularly of significance to this paper is the groups getting engaged in activities of thrift saving (micro credit) and making alliances with other marginalised groups to struggle for land, housing and so on. The milestone of this approach is that disabled people both men and women contest local authority elections (Panchayat).

These impacts have been possible because of the socio-political consciousness of this mass of people with respect to disability and the larger issues of poverty.

Among other key players, the NGO in question also played a role in influencing the Ministry of Rural Development, Government of India to make financial resources available by way of grant in Aid to NGOs undertaking organizational work of disabled people. This has brought legitimacy to this approach with the Government of India .

Disabled peoples Organizations and Poverty

For more than a decade disabled people's organization (DPOs) have sprung up. These are made up of well meaning elite disabled people. These DPOs are championing the cause of disabled people. Many of them are organizations without a mass base. They have paper membership sometimes running in to thousands. Neither do they have the methodology or mechanism nor a comprehensive understanding of the root causes of poverty and how these link with the liberation or otherwise of poor disabled people. So much so that these DPOs are not known to join hands with other marginalised groups to struggle against fundamental issues that affect the poor, such as land reformation, minimum wages, and protection against all forms of exploitation. Equity and justice begins for DPOs with transport concessions, disability pensions and such like and ends with integrated education, employment reservation and income tax -reduction.

Those DPOs who purport to organize disabled people at the grass roots, do so by disability wise. This practice is divisive in that it divides disabled people of different types. Already the numbers of disabled people is small and practices that knowingly or unknowingly divide them can only make disabled people weaker in their attempt to organize themselves.

In the absence of poor disabled people's constituency to consult, Donors and Governments are left with no option but to consult DPOs. For the reasons stated above, the very DPOs who purport to champion the cause of poor disabled people become a stumbling block to the millions of disabled people. The whole sale aping of the ideology of the western DPOs by the DPOs in the third world is another constraint to development. Only the disabled should work for the disabled and all professionals should be under the control of DPOs are just two examples of how counter productive such practice is in the third world context. In the first place, there are not enough professionals to work with disabled people and secondly the issues of disabled people in Third World Countries are bread and butter issues like the majority of the non-disabled population in the countries where they live. There are no DPOs to speak off in these countries except in the capitol and in other major cities.

Lessons from a recent study.

The executive summary of a project initiated by the Ministry of Welfare, Government of India follows to illustrate that 're-thinking care ' on disability has to be inclusive with other poverty and development concerns if it has to have any impact on the lives of poor disabled people:

Background: With rapid urbanisation and the growth of urban poor communities, the Indian Ministry of Welfare is seeking an appropriate model of service provision for persons with disabilities in urban areas. Any model should take into consideration both the special characteristics of poor urban communities, and the experience and performance of urban services. The Urban Community Based Rehabilitation (UCBR) Project was set up to do this.

Aims

- To conduct community studies in low-income communities in Bangalore, Calcutta and Visakhapatnam to explore the expressed needs and experiences of person with disabilities and their families in low income communities and experiences of existing services in relation to these needs.
- To evaluate eight approaches to service provision in the three cities in relation to these needs.

Methods: 587 persons with disabilities and their families from randomly selected slums in three cities, Visakhapatnam, Bangalore and Calcutta, were interviewed by questionnaire covering socio-economic, socio-cultural information, community life, service use, plus qualitative discussion of needs. 22 focus group discussions (FGDs) covering 144 persons with disabilities and family members were held to discuss experiences and needs. Eight service approaches, including government and NGO, centre and community based were studied. A questionnaire was used with a random sample of 492 service users covering socio-economic, socio-cultural information and service use. 40 FGDs explored with 240 people, socio-economic, socio-cultural information, and experiences of service. Individual and group interviews were held with staff members about staff attitudes, and service costs. For a range of 6 impairment groups, the service use of a total of 60 persons with disabilities was both observed and followed up afterwards, in order to measure the quality of medical rehabilitation.

Results & recommendations

Disability and poverty must be addressed together

- Whatever the situation, the additional costs of disability makes families poorer. The needs of persons with disabilities should be included in mainstream urban poverty eradication programmes. The principle of inclusion means that persons with disabilities and non-disabled people have equal opportunities to share in mainstream activities. The barriers that prevent such inclusion, which include economic, structural, environmental and attitudinal, should be identified, analysed, and removed.
- Representation of poor persons with disabilities must be a foundation of their inclusion in mainstream development.

This study found that the priority needs expressed by urban poor persons with disabilities and their families are for income and education, priorities in common with poor non-disabled people. 59% of men and 79% of women with disabilities were unemployed. Policy and practice should enable the persons with disabilities and their families from low-income areas to express their own needs in the development process.

The study found that women with disabilities were significantly less likely to attend school or do paid work than men, and were perceived to be exposed to greater risks. Women and girls took on considerable additional work in caring for persons with disabilities, in isolation, and without support. Policy must ensure the equal representation of poor urban women with disabilities and female care givers to express their specific needs through a community based approach.

This study found that a barrier to persons with disabilities' inclusion in structures is the excluding attitude of staff in government departments, community development, public transport, hospitals, schools, NGOs, urban development, and donors. Awareness and action training on disability and poverty, centred around the social model of disability and barriers approach, and lead by persons with disabilities, should be compulsory for all central and state government staff, municipalities, NGOs, and donors. Persons with disabilities should be included in to the network of community development services, from the relevant Ministries' actions to community level structures.

Most importantly, all urban local bodies such as municipalities, corporations, and community development societies should ensure adequate resource allocation for the implementation of inclusion of persons with disabilities in all their programmes, including support for the informal sector, such as self employment schemes and allocation of space for small and medium sized enterprises. Inclusion can be enforced through budget allocation, much as all development budgets and activities must include the needs of women. Government and donors should adopt inclusion as a pre-requisite to resource allocation.

Support the family and community: The study found the greatest support for persons with disabilities came from their own families, and their immediate communities, and not from Government or NGOs. The greatest needs expressed by persons with disabilities and their families were economic. Support, including money, should be given to family and community based income generation groups complemented by group managed day care, and emotional and social support. Provision of loans for persons with disabilities already exist in India, but in the three community studies only one of 587 persons with disabilities interviewed had secured a loan. Policy and practice should treat persons with disabilities as a priority group in micro - finance schemes. Loans should be available to care givers when persons with disabilities cannot work themselves on account of their disability.

The study found that five times as many children with disabilities were served by local mainstream schools as by special schools. Mainstream schools should be supported to include the needs of all children, including those with disabilities, within their catchment area by changing National and State teacher training curricula, the physical environment of schools, learning materials, and providing disability awareness training for all staff, non-disabled children and their families.

Centre based services do not meet the needs of urban poor persons with disabilities: This study found that centre based services which focused primarily on medical rehabilitation and segregated education do not include or meet the needs of poor urban persons with disabilities. In one city in which 38% of the community study sample lived in Kutcha (poor) houses, only 4% of users of centres came from this socio-economic group. Thus centre based service provision reinforces inequity. Poor people are unable to access centre-based services because of barriers related to the cost and time of travel. These become increasingly important when non-mobile children get older and heavier.

Centre based services focus on medical needs which are not the priorities of poor people. Medical rehabilitation has a limited role in meeting the needs of the urban poor. It is inappropriate for centre based medical services to manage community based services. Accepting that all services are inadequate, financial and skill resources should be directed towards community based structures that demonstrate that they effectively reach poor people. No additional resources should be put into centre based referral services unless they meet the criteria of equity (priority coverage of those most in need) and quality, and support community based approaches. No additional resources should be put into any other centre based services.

NGO and government roles: This study did not find evidence to support that NGOs are more successful than Government at reaching poor people at community level. The study found that the most important determinant in reaching the urban poor was a community based approach as part of general community development. This was true for both government and NGO services. Allocation of resources for persons with disabilities should continue through the community development structures of both government and NGO sectors.

Monitoring and evaluation: This study found that overage of urban poor persons with disabilities by service organizations is extremely limited. Less than 5% of persons with disabilities interviewed in the community studies had used NGO rehabilitation services. 88% had used government medical rehabilitation services, but the services were of poor quality and expressed medical needs were not met. Government and donors should make effectiveness in meeting the real needs of urban poor persons with disabilities a prerequisite of resource allocation.

The study found that government benefits have extremely limited coverage and are not equitably distributed. Significant barriers to access exist in government structures. Government should monitor the coverage of welfare provisions such as disability certificates and loans, and address institutional and attitudinal barriers to their distribution."

Conclusion

In summary, "re-thinking care" on disability could be considered to be serious and meaning full to the millions of disabled people in the world who live in abject poverty only if such re-thinking not only evolves strategies to include disability concerns as part of the over all development strategies but also is pro-active in combating forces that impoverish the poor and gives voice to poor persons with disabilities.

Paper presented by

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A CALL TO OPEN THE DOOR: A psychiatric disability perspective on ‘rethinking care’, *Mary O’Hagan*

A PARABLE

Once, on a lush, prolific island surrounded by a deep unknown sea, a family lived in a large old house. The family devoted their lives to keeping their house a safe and comfortable place to live. They worked together harmoniously, blending their talents and skills. But gradually one of the family members, who was a painter, changed. She went off on her own and painted strange, incoherent pictures, she and the others could not understand. Everyone felt frightened and helpless.

After a while her family said to her "You have got to go. Your paintings don't belong to this house any more. Our house is no longer safe and comfortable for us." They told the caretaker to lock the woman in the junk shed at the bottom of the property, on the slippery margin between the land and the sea. In the junk shed the woman suffered more terribly than ever, until she made friends with the sea who told her the meaning of her art. Then she started to long for her paints and brushes again. So she asked the caretaker to tell her family that she wanted to come home.

But her family still did not trust her to keep their house in order. They sent a message to the woman saying she could live on the back porch where they would provide her with food and blankets. But life on the back porch wasn't much better than in the junk shed. The woman still was not allowed her paints and brushes and the loss of her art set off a terrible screaming inside her. The caretaker saw her pain and finally convinced her family to open the door and let her live inside the house again.

The woman was overjoyed to be in the house again. She seized her paints and brushes and painted while the others looked on. At first the family still couldn't understand the woman's paintings, but after a while they saw the power of her work. "Where did you learn to paint like this?" they asked her. She replied "When I was in the junk shed I made friends with the sea who told me the meaning of my art. But I didn't know I could paint like this until I picked up the tools I have been denied for so long." Her family realised their mistake and from that time on they gave her a room of her own to decorate and live in as she pleased. And they all lived together in their own rooms under the same roof, happily ever after.

LIFE OUTSIDE THE HOUSE

A brief history

People with psychiatric disabilities have a long history of segregation from their communities. In western countries, before the institutional era, we were confined to attics or poor houses, banished to a vagrant existence on the roadside or hunted and tortured as witches. Over the last 200 years we have been sent to large institutions, well outside the town boundaries where we have often stayed for the rest of our lives. At their best, the institutions offered an artificial community and paternalistic control and care to people who had lost their right to belong to their natural communities. At their worst, they subjected people to abuse, neglect and torturous treatments.

In the wealthy western countries most of the institutions are closing but elsewhere they remain. The segregation of the institutional era is passing but people with psychiatric disabilities have serious reservations about what is taking its place.

The community care era was ushered in by economic constraints, new treatments that ‘normalised’ people’s behaviour, and a growing awareness of human rights. However, community care has largely failed to deliver people back to their communities. Often states have not provided enough resources for community care. Many mental health services have continued to operate in isolation from communities and to treat people with psychiatric disabilities with similar paternalistic control to the institutions. Some people leaving the institutions have ended up on the streets or in prisons.

People with psychiatric disabilities want to be freed from the junk shed but we do not want to end up on the back porch. We want a key to the door and a room inside the house.

People’s experiences

I write this paper as a privileged person from a wealthy and democratic country who has never known abject poverty, warfare or oppressive dictatorships. But I do know the experience of psychiatric disability and I have met others with psychiatric disabilities from many parts of the world. Despite our different cultures, ethnic backgrounds and beliefs, our stories are essentially the same - they are the stories of exiled people who are struggling to find their way home.

People with psychiatric disabilities all over the world talk of their suffering during episodes of mental distress, but worse than that, they talk of their shame, and the rejection they experience from others for something they did not choose.

A large number of people with psychiatric disabilities talk of the horror of being locked up in institutions and being subjected to forced treatment, physical and sexual abuse, and neglect. In some countries people are trapped in institutions for years with no legal processes to help get them out.
Some people say they were put in institutions to hide their family’s shame or to silence their political views.

Millions of people have suffered serious harm from psychiatric treatments. Many people suffer from Tardive Dyskinesia - a permanently disfiguring side-effect of anti-psychotic drugs. Some people suffer permanent memory loss from electric shock treatment. Occasionally people are given lobotomies, a brain operation which permanently flattens their personalities.

A growing number of people talk about not being able to use community mental health services when they need them, because there aren’t enough services to go around, or because the services are too controlling, or because the assistance they provide isn’t what people want.

Millions of people with psychiatric disabilities live in degrading institutions, houses or hostels where they have no say, in dilapidated boarding houses, in prisons or on the street. Those who attempt to live in respectable neighbourhoods often get the message that they are not welcome there.

Many people with psychiatric disabilities, who want to, never find employment on the open market. They are subjected to sheltered workshops where they do repetitive work for a pittance. Or they spend their lives in living rooms and day centres without any opportunity to contribute to their communities.

All over the world people with psychiatric disabilities are joining the underclass of people on the back porch of their communities, where they are condemned to the intolerable multiple stresses of poverty, unemployment, loss of hope, inadequate housing, isolation and exploitation.

But it doesn't have to be this way. These things would never happen in a world where people with psychiatric disabilities were given the treatment, care and support they want, and equal opportunities to their fellow citizens.

THE LOCKED DOOR

There are strong, sometimes overwhelming forces that keep the door locked to people with psychiatric disabilities. These forces involve the way people think as well as their behaviour. Everyone potentially shares some responsibility for keeping the door locked to people with psychiatric disabilities, including people with psychiatric disabilities themselves.

The conceptualisation of mental illness and disability is too narrow and doesn't facilitate recovery

There have been many explanations for mental illness throughout history and across the different cultures of the world, but in many countries the dominant explanation is that mental illness is biological and responds best to medical treatments. Some people with psychiatric disabilities say they have benefited from medical diagnosis and treatments but most prefer more holistic explanations that take into account such things as people's life experiences, social inequality, and spiritual matters.

The debate on the nature of mental illness and disability is more than just an interesting intellectual exercise. A society's underlying conceptualisations about mental illness and disability will profoundly influence the way services are delivered and whether the door to our communities is open or shut to us.

Disability and mental illness are judgements, not facts

Mental health professionals and interested lay people tend to view mental illness and disability as inherent facts about individuals rather than as socially constructed judgements. It is easy to see that having unusual beliefs or hearing voices that others cannot hear are factual occurrences. But attaching the label of mental illness or disability to these facts is purely a judgement. The voices and visions of saints and shamans have made a huge positive contribution to many cultures. How different their lives would have been if they had been judged to have a mental illness instead of a spiritual gift.

Disability and mental illness have no real meaning outside the context of our social relationships and how we understand things like productivity, communication, attractiveness, independence and status. States of being that don't fit society's definition of what is productive, attractive, independent and so on, are likely to be thrown into the disability basket.

The relativity and reversibility of the concept of disability was well illustrated once in a brilliant television portrayal of a 'wheelchair republic' which was designed and controlled by people in wheelchairs. All the ceilings were lowered to accommodate seated people. Upstanding people had to stumble and crawl to get around, and had to wear crash helmets to protect them from knocking into the ceiling. The programme turned the tables and showed how the people in wheelchairs discriminated against the upstanding people who lived in a world that literally and figuratively cramped their opportunities to be productive, independent and valued members of the community.

Perhaps it would be better for people with psychiatric disabilities to live in a world where no one was seen as disabled or mentally ill but simply had minority requirements that other citizens accommodated as a matter of course. Disability would merely indicate the different requirements of certain minorities to live a fulfilling life, rather than all the baggage and labels that say we are helpless, useless, unattractive and needy.

Unfortunately, when disability and mental illness are viewed as inherent facts about individuals, it places these concepts beyond questioning. It also limits the discourse or self-examination by society, on how it may contribute to the causes of mental illness and disability, and how it might perpetuate them through harmful treatments, coercion, and discrimination.

The medical model justifies coercion

The medical model has a long association with coercive practices within the mental health system. It tends to view people with psychiatric disabilities as helpless victims of forces within them that rob them of their competence and rationality. The medical model tends to justify coercion and paternalistic practices on the grounds that these practices will restore people to competence and rationality, and liberate them from their own pathology. Psychosocial models cannot so easily justify coercion and paternalism, especially those which emphasise free-will and personal and social responsibility.

Recovery is taken over by experts

The medical model supports the use of powerful technology such as drugs and electric shock treatment. Only experts in this technology are empowered to administer these treatments which puts people with psychiatric disabilities in a very passive role. Most other therapies used by people with psychiatric disabilities such as psychotherapy, herbal remedies or self-help groups require them to be more actively involved.

Pessimism in mental health services is rife

The preoccupation with diagnosis and prognosis is most pronounced in those who adhere closely to the medical model. They believe that the so called major mental illnesses have a fairly pre-determined course. This tends to make people with psychiatric disabilities feel they are condemned to recurrences or deterioration in their condition, which can in fact be quite wrong. The medical model, especially when it is not combined with other explanations and therapies, encourages people with psychiatric disabilities to sit and wait for a terrible fate which they have no power to change.

People with psychiatric disabilities are discriminated against

Discrimination is the most painful, widely felt and insidious problems for people with psychiatric disabilities.

Discrimination takes many forms. It may mean that we are the subject of ridicule, harassment and abuse. Or we may be simply forgotten or ignored. We are likely to be feared and avoided because of our perceived violence, dishonesty and unpredictable behaviour. Our expressions of anger and pain can be dismissed by others as symptoms of our illness. We are sometimes subjected to excessive pity and the belief that our lives are sad and have little value. We are often told we will never get better. We know that if we talk about our experience of mental illness or distress we may lose our friends or be denied the house or job we want.

Discrimination against people with psychiatric disabilities can be as subtle as the look in someone’s eye or as blatant as the murder of people with mental illness by the Nazis.

People with psychiatric disabilities can experience discrimination in any interaction they have with any other human being. These people may be their families, neighbours, employers, the police, judges, health professionals, the clergy, government officials, voluntary agencies, other people with mental illness, landlords, bank managers, insurance agents, politicians, journalists, friends, partners, immigration officials, workmates, lawyers or sports associates.

And people with psychiatric disabilities, in painful collusion with others who discriminate, often see themselves as others see them.

Discrimination by the state

It is the role of the state to create the conditions where all citizens have the opportunity to lead fulfilling lives and to contribute to their communities. States vary on how they do this. In many countries the state both funds and provides services for people with psychiatric disabilities. But there is a trend in some western countries for the state to pull out of provision and to fund communities and non-government organisations to provide for the needs of their people.

States have discriminated against people with psychiatric disabilities in several ways. States have been responsible for the chronic under-funding of services to assist people with psychiatric disabilities. Some people with psychiatric disabilities believe the state discriminates through empowering mental health services to forcibly treat and detain some people with mental illness. There is a growing trend for the state to impose compulsory treatment orders on people living outside institutions. States have also done too little to stop communities from excluding people with psychiatric disabilities, through the absence of legislation and policy that give us equal opportunities with other citizens to live in decent housing, to work, and to have an adequate income.

Discrimination by mental health services

Mental health services can also discriminate against people who use the services. They do this through coercive and paternalistic practices, failure to involve us in decision making, and failure to deliver the services we really want.

Coercive and paternalistic practices are not just features of life in institutions. Unfortunately these practices remain alive and well in many community based mental health services. Clinical services can decide what treatments we have, what information to give about them and they can harass us in our homes with assertive community treatment programmes. Accommodation services can decide where we live, who we live with, what time we go to bed and what we eat. Vocational services can decide what we do during the day and if we are ready for work or not. Other rehabilitation services may decide what we do with our money, what life-skills we lack, or where we go shopping.

Many services still assume they know how to provide a good service for people with psychiatric disabilities without even asking us. The people using those services often have no power to change the services, or go to other services. Many mental health services continue to treat us without respect, equality and protection of our rights, especially our right to informed consent.

Discrimination by communities

Communities actively discriminate against people with psychiatric disabilities in many ways - when neighbours say they don’t want us to live in their street, when employers won’t employ us, when our workmates tease us for having a mental illness, when people joke about us, or when our friends desert us.

But communities also passively discriminate against people with psychiatric disabilities by abdicating too much responsibility for our lives, often to the state. People require specialist services when their communities no longer have the ability or the will to provide them with the things they need. All communities recognise that most people don’t have the ability to do some specialised tasks such as surgery, plumbing or computer programming. But communities don’t always demonstrate they have the will to see to the ordinary needs of all citizens for housing, income, work and family life. With the exception of specialised treatments, such as drugs for mental health problems, the ability in our communities is there but the will is not.

When people with psychiatric disabilities need a specialist service for things like housing, income, and work, our communities have abdicated their responsibility for maintaining our ordinary needs. The sad reality is that no specialist service can cater for these ordinary universal needs as well as willing friends, peers, families, clubs, community groups, neighbourhoods or business communities.

People with psychiatric disabilities continue to live in ghettos, often run by the state, not just behind the high walls of institutions but also in community based service networks where all the people they know are other service users or people who are paid to be there.

People with psychiatric disabilities are seen as victims who are unable take responsibility for their own lives

People who are regarded as helpless, who are controlled by services, and who are excluded from their communities often find it enormously difficult to discover, develop and use their own personal resources. Yet people with psychiatric disabilities who have regained their lives, often say that using their strengths and abilities to take responsibility for themselves was the most important factor in their recovery.

Too many people with psychiatric disabilities sit in mental health services year after year. They are often over-medicated and under-motivated. Their sense of personal development died the day they were given a diagnosis or told they would never get better. Their self-respect has been shattered by degrading treatment and discrimination. They have lost hope and the belief that could make a better life for themselves. This is a tragic waste of human potential.

It is not just the state, mental health services or communities that perceive us as victims. Individuals with psychiatric disabilities often believe this of themselves. The psychiatric survivor / user movement, and others who advocate for our rights and inclusion, can also inadvertently contribute to our victimhood. Human rights activists and the survivor / user movement have contributed enormously to our understanding of the oppression and discrimination of people with psychiatric disabilities. But sometimes we have stayed stuck in our analysis of our powerlessness and in the powerless roles we have grown so accustomed to. As people struggling to emerge from oppression we do not always recognise what power we do have to change ourselves or the people and systems around us. We also hold a key to the door.

THE KEY TO THE DOOR

The psychiatric survivor / user movement

Some brave individuals with psychiatric disabilities have stood up for their rights throughout the last two centuries, but the psychiatric survivor / user movement did not begin to organise until the early 1970s. The movement started in Europe and North America. Since then it has spread to other western democracies, the former communist countries of Eastern Europe, southern Africa, Japan, as well as Central and South America. Like the feminist, civil rights, gay, indigenous and disability movements, the survivor movement is based on the principle of self-determination. We believe that people with psychiatric disabilities have suffered too much coercion by the mental health system and exclusion by our communities. People with psychiatric disabilities must have the power and resources to determine their own lives.

The survivor / user movement works on two main fronts - self-help and political action. In self-help we aim to change ourselves and recover from our experiences. In political action we aim to change the people and systems that affect our well-being.

It is not uncommon in some countries for people with psychiatric disabilities to run their own services and support networks. These may be drop-ins, crisis houses, arts projects, housing projects or small businesses. Services run by people with psychiatric disabilities usually have a strong commitment to the full participation of people using the service and to honouring their rights. Self-help initiatives provide valuable clues on how we want all our services to be.

Some groups within the user movement have campaigned against forced treatment since the movement started. Forced treatment has not been outlawed anywhere in the world, but in many countries it has become more difficult for the state to detain or treat people against their will. However, there are worrying signs in parts of Europe and North America that more people with psychiatric disabilities will be subjected to compulsory treatment in the community. The user movement has also campaigned for the closure of institutions, a broader range of treatments and supports than those offered by most mental health services, and for people with psychiatric disabilities to have equal opportunities to other citizens.

People with psychiatric disabilities are also working from within the mental health system to develop more responsive services. In many countries we now advise governments on policy, take part in funding decisions, and participate in the planning, delivery and evaluation of services. As individual service users we are more likely to understand the controversy that surrounds the causes of mental illness, seek different options for our treatment and support, know our rights, and question decisions made about us by service providers, than at any other time in history.

Universal human rights

The Universal Declaration of Human Rights is now 50 years old. It was developed in response to the horrific human rights atrocities committed by Nazi Germany. The Declaration marks the beginning of an era where all countries in the world are expected to protect the human rights of all their citizens. Many other rights statements, that build on the Declaration have come out of the United Nations since then. They are all as relevant to people with psychiatric disabilities as they are to other citizens. The are two statements that most specifically address the rights of people with psychiatric disabilities.

The Standard Rules on the Equalization of Opportunities for People with Disabilities

The Rules assert that all states are responsible for removing obstacles to the equal participation of people with disabilities in the areas of:

- access to the physical environment, information and communication
- education
- employment
- income maintenance and social security
- family life, sexual relationships and parenthood
- cultural activities
- recreation and sports
- religion

The Rules also state that people with disabilities need adequate care and support as preconditions for accessing equal opportunities, and that they must participate at all levels of policy development and service provision. It is considered that all states fall short of fully implementing the Rules.

The UN Principles on the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care

This document focuses on the right to treatment and services but unfortunately does not offer any guidance on the protection of the rights of people to refuse treatment. This is a glaring omission according to many people in the survivor / user movement around the world.

Services that show us through the door

Despite the poor performance of many services, some mental health services do assist us greatly to regain our lives. These service have various features in common. These are the services we want.

We want access to services that respond to our stated needs whoever we are, and wherever we are, and whenever we need them.

We want services which at the very least will do us no harm
All the treatments and supports services offer people must give the most possible benefits and the least possible adverse effects.

We want more ways to understand and deal with our mental distress than those offered by the medical model
Mental health services are still dominated by biological explanations and treatments. People with psychiatric disabilities often believe there are many explanations for their mental distress and many types of treatment and support that might help them, such as natural healing, psychotherapy, education for recovery and assistance to find work, housing and community contacts.

We want less pills and more assistance to regain the social and material opportunities we have lost
Services need to help reduce our mental distress or unwanted features of mental illness, but they need to put as much effort into assisting people to counter isolation, poverty, unemployment, discrimination and anything else we may have lost in the wake of our mental distress or illness.

We want voluntary not coercive services
Some of us believe that forced treatment and detention are human rights violations which can never be justified. For those of us who have lost our rights to full autonomy, mental health services must take place in the least restrictive setting and use the least possible coercion and restraint for the least amount of time. To avoid forced treatment we want to determine what happens to us in a crisis through the use of advance directives or crisis planning.

We want the power to choose the services we want and to change the ones that aren’t working for us
Mental health services must offer the most possible autonomy and choice to people with psychiatric disabilities about our treatment and the support we need for our recovery. Services must involve service users as equals in all decisions made within the service that affect our lives. If we are unhappy with the service, we need a fair and easy process for making a complaint and ensuring they get better service in the future.

We want the skills and resources to run our own services and other opportunities to use our competence
As individuals we need to take an active part in decisions about their treatment and support. As a collective we must be involved in the planning and evaluation of services at all levels. States must support the user movement to develop support networks and user run services. There should be no barriers to people with psychiatric disabilities working in mental health services.

We want a way out of mental health services
Mental health services should never try to replace natural communities - they are there to carry out specialist tasks and roles the rest of the community is unable or unwilling to perform. People with psychiatric disabilities need skills and encouragement to reduce their dependence on mental health services. Services need to ensure we have education on mental illness and health, treatments, crisis planning and prevention, maintaining a healthy lifestyle, countering discrimination, rights and self-advocacy, using support networks and using community resources.

Communities that welcome us in

Communities, with the backing of the state must be much more active in ensuring the rights and welfare of people with psychiatric disabilities**.**

We want the same rights, responsibilities and opportunities as other citizens
People with psychiatric disabilities need their rights protected by legislation. Governments need to ensure that we have equal opportunities to other citizens. No country should deny us education, work, income support, goods and services, housing or the ability to belong to a neighbourhood or a family. Families, communities, health and welfare agencies must support us, or at the very least, ensure they do nothing to impede our participation in our communities. The people in our communities whose lives and decisions have an impact on us, need to act towards people with psychiatric disabilities in a spirit of respect, equality and inclusion.

We want equal access to education and employment
The knowledge that we have a psychiatric disability should never deter employers or educators from taking us on if we are otherwise qualified. Once we are in educational settings or workplaces, some of us need reasonable accommodations such as flexible scheduling and sick leave, or additional supervision and support. If possible governments need to compensate employers and educators if they use extra resources to make reasonable accommodations.

We want an adequate income
Employment is the best route to securing an adequate income but if this is not possible governments should provide enough income for people to meet their basic human needs and any other needs arising from their disabilities. In some countries income support from the government acts as a disincentive for people to work who fear they will lose their financial security if they return to work or that working will earn them no extra income. Governments need to find creative solutions to this problem.

We want reasonable housing

We want to live in a place we can call home, not institutions or on the street. We want homes that are comfortable and shelter us from the weather. We want to choose where we live without fear of objections or hostility from our neighbours.

We want to belong to a family

People with psychiatric disabilities want the the support and opportunity to make friends, establish relationships and become parents without fear of losing custody of our children.

SUMMARY

People with psychiatric disabilities, in all corners of the world, live in the junk sheds and the back porches of their communities. In recent times we have begun to knock on the door to our communities and demand that it is opened to us.

Governments and mental health services have to acknowledge the uncomfortable truth that the ‘care’ of people with psychiatric disabilities often supports the practices of paternalism, coercion, discrimination and exclusion. As states, mental health services and communities enter the 21st century, their attempts at ‘rethinking care’ must do away with these practices. Instead, ‘care’ must be concerned with standing alongside people with disabilities to assist us, on our terms, to open the door to freedom, inclusion and a valued place in our communities.

Discussion paper prepared by Mary O’Hagen

RE-THINKING CARE FROM A RIGHTS PERSPECTIVE, *R. Hurst*

Introduction

The right to life itself is implicit in the fundamental right of each human being to be born free and equal in dignity and rights. This paper aims to show why the right to life, dignity and freedom should be the fundamental principle underpinning all policies and practices concerning health and social care. Without the firm application of this principle the outcome of any social support will be to deny individuals equalisation of opportunities, exclude them from the mainstream and deny them the right to self-determination.

Much recent research has clearly demonstrated that traditional methods of service provision which target the needs of the group rather than the individual and are based on the needs and resources of the service provider, have been shown to be ineffective, costly, discriminatory and, in some cases, violate individual's rights.

What is Care?

From the perspective of disabled people, the word 'care' does not send the right message. It firmly puts the power with the care-giver rather than the recipient. Attention is focused on the context from which the giver operates rather than a context in which the recipient should rightfully and equally participate. It is inappropriate to use the word 'care' in relation to people who are paid for doing a job, often have a professional structure to support them and gain social status from their work. It is similarly inappropriate to use the word 'care' in relation to the manifest duty of governments and statutory authorities, under Article 25 of the Universal Declaration and also, in many cases, under civil law, to support those people who, through no fault of their own and, for such reasons as age, ill-health, disability, widowhood and unemployment, are unable to access the same opportunities as others. 'Care' is not an appropriate word to describe putting someone into residential accommodation where they have no voice and cannot even determine what time they get out of bed or what they wear. 'Care' is not a word to describe services that ignore an individual's cultural and relationship needs, that cuts them off from their peers in day centres or which gives rehabilitation or training in isolation from families and then gives individuals no alternative but to beg. 'Care' cannot describe the rights that the judicial system often exerts over people who cannot speak for themselves. Nor can 'Care' describe the lack of information and the subsequent lack of informed choice of disabled people in many situations. Even with regard to 'informal care-givers', those family members and friends who often give up much of their time and energies to support their ageing or disabled relatives, the word 'care' puts an unnecessary burden of powerlessness and passivity on the part of the recipient and can infringe their personal dignity.

For the purposes of this paper I will concentrate on service provision - not care - and how those services can be provided to support the rights of the individual through facilitation and support - not care - from governments, authorities, professionals and lay members of the community.

Cost Implications

If we agree with the Universal Declaration that all human beings are born free and equal in dignity and rights and that no individual's right should infringe another, then it follows that services and social structures should be provided in the community, as part of the community, without discrimination. Society or any person acting on its behalf, cannot make an assessment of whether one individual is less or more human than another or more or less eligible for services. They are either eligible or they are not.

Yet many governments and authorities penalise those disabled people who need more services. For instance, UK law says that if you cost more than £500 per week to live independently in the community then the local authority can insist that you live in an institution. Similarly, in most states in Canada, if you are dependent on a ventilator for daily survival then the State will only support you within a hospital setting - not within your own home. Clearly these policies and practices violate the rights of the individuals, do not support dignity or freedom and - incidently - are more costly.

Many expensive medical interventions and treatments are denied people on the grounds of their life-style or impairment. In many countries, people with Downs Syndrome have taken health services to court for contravention of their right to have a heart transplant. A recent survey by the Downs Syndrome Association in the UK has shown that 40% of their members faced discrimination on the grounds of their impairment in the provision of health treatments. This discrimination in the provision of health services is replicated by the experience of people with other impairments. And much of this discrimination is covert. For example, almost daily, medical practioners in the UK National Health Service make decisions about who should receive kidney dialysis from the too few machines available. These decisions are based on a judgement of quality of life and responsibility. Those in work and with a young family are far more likely to receive treatment than a single young man. The excuse given for these judgements - and many more with regard to all sorts of treatments - is lack of resources or undue costs. Keeping these quality of life judgements secret and focussing the blame on lack of machines deflects a proper analysis of why there are not enough resources. Health service administrators and governments can feel satisfied that the system gives an appearance of providing, albeit not to everybody, and the discrimination can be kept hidden. The individuals concerned are seldom told why they are not getting the treatment. They are not given the proper information from which they can maintain their self-respect and dignity, nor are they able to effect change through the proper democratic channels to ensure that resources are used in a non-discriminatory way.

Undoubtedly there are many countries in the world where resources are scarce and debts are high. However, much recent research has shown that if poverty is to be alleviated and development sustained, policies, market forces and social services must be provided and resources allocated on a basis of human rights. Governments cannot spend money they have not got, but they can make decisions on how to use the resources that they have got in a way that does not discriminate and which does the best it can to uphold the right of every person to freedom and dignity.

Quality of Life or Disability Adjusted Life Years (DALYS)

I have touched on the use of judgements on a person's quality of life as a way to overcome lack of resources. DALYs are a professional tool used by many doctors and health professionals to formulate policies and health plans. One argument to support DALYs is that they allow clinicians to make better judgements on treatment if the DALYs are used to assess the impact of a particular drug. Unfortunately, DALYs and quality of life assessment methods have been used to assess individual's eligibility for treatment and are now becoming more and more fashionable as health costs mount and competition between professionals becomes more intense. DALYs are also being used by many geneticists to provide a rationale for the eradication of impairment from the gene line in efforts to produce perfect people.

The reality is that the impaired gene, embryo, feotus or disabled person becomes a commodity to be bartered, exchanged or discarded at the whim of the market - not a person or potential person with equal rights and dignity.

And it becomes more and more evident that the major force that operates this market is the prejudice that disabled people are not entirely human and therefore do not need to be accorded the same rights as non-disabled people.

As a result of this prejudice, evidence is mounting that disabled people's lives are at risk when they seek medical treatment:

- *Since the introduction of legal voluntary euthanasia, research in Holland has shown that thousands of people, including people with intellectual impairments, are receiving euthanasia involuntarily.*
- In many countries, such as the US, Canada and the UK, Do Not Resuscitate (DNR) notices are being put on the medical files of disabled people without their permission.
- Only recently in the UK a middle-aged, married woman with a high-powered job went into hospital with pneumonia. Because she also had muscular dystrophy the ward doctor put a DNR notice on her files without her permission.
- The Headmistress of a day school for disabled children wanted to have a DNR policy to ensure that some of her pupils who had life-threatening symptoms would be, as she said, 'allowed to die with dignity'. She described these children as terminally ill. It was the same as saying that an insulin-dependent diabetic was terminally ill and should not be resuscitated if they went into a state of hypoglaecemia.
- The leading neurologist at a prestigious UK hospital and residential home for people with severe neurological impairments has shown that 40% of his patients who had initially been diagnosed as being in a permanent vegetative state (pvs) were not so and in fact have since communicated and even completely recovered from their comas.

Adding to the above outcomes, our inhumanity is being emphasised by leading geneticists, philosophers and ethicists who are publicly saying that disabled people should be screened out of the gene-line, that parents who knowingly give birth to a disabled child are immoral, that it is acceptable for doctors to make no efforts to resuscitate disabled infants and that the life of a healthy monkey is more valuable than a disabled child. These statements taken individually would not necessarily cause great concern but when seen together they clearly demonstrate that there is a large body of influential opinion that does not support the right to life of disabled people nor see us as full human beings.

Conclusion

These inhuman and eugenic attitudes must have an impact, however subliminal, on the provision of services and resource allocation. Denial of the right to life is the antithesis of seeing disabled people as we should be (and sometimes almost achieve) - fully participating members of our communities, whose different humanity should be celebrated as an important contribution to society as a whole and without which society itself would be poorer. Unless service providers and policy-makers understand that this life-threatening attitude is prevalent and must be overcome and that structures, systems and policies for which they are responsible, must uphold disabled people's rights, no real sustainable progress will be made toward a society where all human beings are born free and equal in dignity and rights.

Rachel Hurst
Disability Awareness in Action
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RETHINKING CARE: THE PERSPECTIVE OF PERSONS AFFECTED BY LEPROSY, *P.K. Gopal*

Leprosy is one of the oldest diseases of mankind. For many generations leprosy was considered as a disease of human mutilation, rejection and exclusion from society. It has unique social dimension. Fear of the disease has remained as a characteristic social attitude of people from ancient period.

For many centuries there have been misconceptions over the disease. People believe it is an incurable disease. punishment of god, etc. High level of stigma prevailed against the disease. Therefore, the patients are reluctant to come for treatment at the early stage, fearing rejection from the family and community. In the past, large number of patients was abandoned by their families and communities. Patients were compulsorily isolated from the community by law. In some countries the patients were not allowed to marry and/ or to have children. Though women are less afflicted by leprosy than men, the women socially suffer more than the men when afflicted with the disease.

In no other disease the patients were forced to leave their families and communities. This had happened in leprosy. The abandoned patients started to live as groups and these places were later called as leprosy colonies, leprosy vil1ages and leprosy settlements. In India there are about 300 leprosy colonies, in China there are 600 leprosy villages and there are many leprosy settlements in all the leprosy endemic countries.

Effective drugs to cure leprosy has been discovered and introduced only in the 1950s and 1980s. There were 12 million leprosy patients in the world when the new treatment known as Multi Drug Therapy was introduced in the 1980s with the combination of three drugs. There has been a great success with the Multi Drug Therapy. About 10 million patients have been cured in the last two decades. Many of the cured persons are still living with physical. psycho-social and economic disabilities.

Rethinking care in leprosy:

In the field of leprosy a definite rethinking in the care of persons affected by the disease is very much needed in view of the following situations:

- As per the guidelines of World Health Organisation vigorous work is being carried out in all endemic countries to eliminate leprosy as a public health problem. This means to reduce the number of patients in a country to one per 10000 population. Hence, the main concentration of work has been to reach the goal of 'elimination'.

- Very little work has been done to restore the normal life of persons affected by leprosy. Mostly the non-government organisations are involved to provide assistance for the rehabilitation of persons affected by leprosy. There is a need to increase this kind of activities to restore the social and economic status of persons to lead a dignified life. Community support needs to be mobilised in this direction.

- The vertical programmes conducted with the exclusive staff to provide leprosy treatment is being dislodged due to the integration of leprosy treatment with the general health care services. As a result the infra-structure so far available to reach the leprosy affected persons is fast disappearing. Hence there is an urgency to develop and implement programmes for integration of persons affected by leprosy in the society. Rehabilitation facilities available for other disabled persons should also be made available for the persons disabled due to leprosy.

- According to WHO there are about 3 million leprosy affected persons with physical deformities in the world. As per the sample study conducted by the author in India about 34 per cent of the persons affected by leprosy need some kind of help to lead a normal life.

Persons affected by leprosy as partners:

- Due to high level of stigma in leprosy, persons disabled due to leprosy did not come forward openly to fight against the injustice done to them, or to claim their human rights, etc. Educated and rich people when afflicted with leprosy preferred to be anonymous to hide the disease. The poor leprosy affected persons have been neglected by the community.

- Therefore, in the field of leprosy, for a long time in many countries, there was no initiative from the persons affected by leprosy to join together, to create a common platform to work for their own improvement. to voice their needs, problems and opinions.

- In Brazil and South Korea the persons affected by leprosy have joined together, formed associations to fight for their rights, to educate the public and to improve their living conditions. In 1994 persons affected by leprosy from 9 countries met in Brazil and founded the International organisation of persons affected by leprosy. The name of the organisation is IDEA which stands for Integration, Dignity and Economic Advancement of persons affected by leprosy.

- In the last five years IDEA witnessed a tremendous growth and support from various national and international organisations and individuals. IDEA, The International Association for Integration, Dignity and Economic Advancement is an international network of support that seeks to end social isolation that is often associated with leprosy.

- IDEA operates on the principle that stigma associated with leprosy and the accompanying social isolation will only be eliminated when those who have personally experienced this disease have regained the identity, self-confidence and dignity that is all too often taken away from them by the disease and Society's treatment of them.
- In order to develop the skills and to build capacity among the persons affected by leprosy IDEA is regularly conducting advocacy programmes to empower them with knowledge. IDEA has national level coordinators in 15 countries.

- The Governments, national and interrnationa1 NGOs should rethink to change their policy to take persons affected by leprosy as equal partners and give them opportunity to work with them in delivering their services to the leprosy affected persons.

- In conclusion, IDEA is dignity and honour. It is public education. It is a pathway of hope for the persons affected by leprosy. It is an international network of support. It is partnership rather than at the receiving end. IDEA is a process, which aims to achieve psychological, social and economic empowerment of persons affected by leprosy.

- IDEA: the organisation of persons affected by leprosy need to join with the organisations managed by persons with other disabilities both at the International and at the national levels. To move forward in this direction IDEA is looking for new opportunities.

By Dr P.K. Gopal, President (International Relations), IDEA.

RETHINKING CARE: A PARENT'S VIEW, *Garé Fabila de Zaldo*

The 20th Century is coming to a close and there is still lots left to do in all countries to improve the quality of life of people with disabilities. There is no country which offers a perfect service and in which, the conditions of life are ideal. In any case, persons with disabilities, their families and members of the society have brought about a social conscience and a vision of the future, which has been the driving force, which has permitted for a gradual change to happen, in the reality of the countries of the world.

The services offered to people with disabilities should be based in a philosophy of solidarity, which is distant from materialism, bureaucracy, personal interests, racism, superiority complexes and egoism. These services should have a *mission*, which will serve to give meaning to our lives and those of people with disabilities and which, emphasize the *vision* of what we want for our Society and for people with disabilities.

> Mission*:* *To promote the improvement in health, education and all services which can help in the development of a better quality of life for people with disabilities.*
>
> To build partnerships between people with disabilities, their families, their communities, systems providing public and private services, as well as, the government. This partnership be made with the objective of joining forces in order to develop material and human resources which will permit that all people are able to obtain the necessary support to be able to develop themselves to the maximum of their potential. At the same time, which allow that best conditions can be achieved for communities.

CARE

Care should be more than just caring, providing services or taking an interest in the resolution of problems. It should include:

- Our love for human beings reflected in our unconditional participation in support of the most vulnerable people in the provision of health and education services, social security, community development and the promotion of their social integration;
- An international social movement of human beings supporting other human beings, based on the love which should exist amongst all of us and the knowledge of the rights of all human beings which facilitates involvement, interdependence, commitment, and personal, familiar and institutional responsibility to the benefit of human beings;
- Our empathy towards situations of disadvantage and the vulnerability of other human beings who are handicapped, poor, old, discriminated upon, abused, etc. Conditions which are distinct from ours and in which, we recognize the potential to improve the services under our responsibility and the different situations of life. Using our knowledge and abilities to offer a better quality of life for them becomes more important, especially when there are adverse conditions.
- The recognition of the existing potential of persons with disabilities and their families who, in the majority of countries, have lived under terrible conditions and, in some cases, even sub-human conditions. Therefore, they have been unable to develop their potential on account of being segregated and marginalized from any opportunities. This is the time for change and the participation of all of us will be decisive on

whether the change can be achieved. The social conscience of the importance of our work will make the difference in putting together human lives and building a new World;
- Its a commitment which we take with ourselves and with the rest of human beings, for a common good based on the respect towards the value and dignity of other human beings, in tolerance and social justice;
- Based on the ethic of values such as honesty, integrity, commitment, faith, justice, consideration and respect for others and the search for excellence to the benefit of those who are most in need.

Care is to have love, respect and empathy in order to be able to evaluate honestly the different services that are offered and the conditions of life of such human beings, for example, our children, parents, brothers, friends, students and patients with disabilities. So as to be able to change their reality for the better.

Each one of us, as members of society, needs to self-evaluate our participation towards providing better services and relations, which support the needs of people with disabilities. This evaluation should bring out the desire and the need to study better, bring ourselves up-to-date. It should also help in discovering new technologies, which will help in planing improvements and to target economic and human resources that may be needed. We need to understand, that people with disability don't know about many things because we have not given them the opportunity to learn, and they need to learn in order to be more efficient and independent.

We have a desire to share our experiences, analyse our problems, results and achievements, in order to be able to help and plan better services, taking into account the experiences of other places. However, without forgetting that the best model for a region is that which satisfies the needs of that place within the local socio-economic and cultural context. It must take advantage of its own resources, learn about its own weaknesses and strengths. Only then the optimal strategies for the development of the community can be developed.

Social Movement

In all countries of the world we find that persons with disabilities must face social injustice. In some countries, their conditions of life are still undignified, degrading, undemocratic, whilst in other countries, important achievements have been obtained in all sectors of the society so that people with disabilities also form part of the society.

We find that, at the end of this millennium, people with disabilities and their families, professionals, friends, and sometimes, government people, can come together. Their aim is to change the quality of life of people with disabilities, for the collective training of a community with all of its members. They may also promote forming a union of all these human beings as a "social force" which, asks for changes in all societies of all countries.

The movement has begun, throughout the world, with the families of children with disabilities since many years, gathering strength and growing to the point of unifying itself with the movement of people with disabilities, professionals and all sectors of the society.

This social movement has come into existence to express our pain, frustration, nonconformity and rebellion against the existing conditions in our communities for our children, brothers and friends. It is also to express our needs, desires, dreams and our fight to achieve equality of opportunities, and better support to the family and people with disabilities in the community. It is a movement against the social injustice that people with disabilities and their families have been living for centuries. It is to denounce the sexual, physical and psychological abuses which have been committed against people with disabilities and their families. It is to fight for the support that the society should provide to the family who has a member with a disability. It is to act against intra-family violence for which, often the victim is the person with a disability and often associated to poverty which increases their vulnerability. Such violence is increasing and it also exists in the rich countries.

Community

Community is the group of people who live in a particular area, which shares the same characteristics and environmental resources. However, we know that this is not the case with respect to people with disabilities, since they have been marginalized from almost all the opportunities that the community can offer. For many years, people with disabilities have been classified according to their defects and inabilities, thus indicating their exclusion from society and the shape of their future, from their very birth. This has brought about that, in the case of children with severe mental retardation, they are denied their right to life, nutrition, health and education. According to previous definitions, it was said that people having intellectual deficiencies were those whose intellectual ability was well below average and whose, adaptive behaviour was demonstrably limited from an early age of development during childhood and early adolescence. This justified their being labelled and excluded from society on account of a low IQ score.

In contrast to this, Marc Gold (1980) defines intellectual deficiency as “being the level of energy, creativity, knowledge and determination which we need in order to teach those people, in order that they may learn without taking recourse to their limitation as a justification for them not to learn.”

Consider the following statement made by a teacher, who said that his level of functioning is determined by the availability of a technology of learning and the resources that the society provides and not by the significant limitations of their biological make up. This definition makes clear the responsibility that we all have as a society to fight for and defend the rights of people with disabilities. We have to use our love and determination in support of people with disabilities, even in the most serious of cases, in order to ensure a good quality of life for them. We have to assume the commitment to ensure that the society provides the necessary resources and promotes the participation of people with disabilities in all of the existing aspects of their own community.

The policies for social integration signify, therefore, the elimination of all social, cultural and economic barriers, which exist within the community. At the same time, it requires the design of services and support needed to facilitate their development and integration in the community life and to promote relations between people with and without disabilities.

We can not speak coldly about human relations, but rather of the importance of developing the concept of “comradeship” amongst human beings from an early age amongst all children. We have to change our society - this concept should be systematically integrated within all services and among those who provide those services, thus facilitating the community life of people with disabilities and maintaining solidarity with them.

This signifies that we should provide:

X Support, assistance and welfare services to people with disabilities and their families, sometimes in a transient way and, in others, throughout their lives. This should be the case in large and small cities, as well as in the rural sector and even in the remote regions of the jungle;

X Opportunities for them to interact in all aspects of community life;

X People with disabilities should have opportunities to have relationships with different people, to have different interests, to grow up, to have education, etc. This increases their opportunity to learn more, have more comrades and form part of the community and we will be enriched by their presence in the society.

Often people with disabilities have a small circle of friends, limited to their family, teachers, therapists or care-takers. They need to be involved with a larger number of people of their same age who are with or without disabilities, with their doctors and teachers, as well as with friends who are there, within the community where they live. It is necessary that these contacts be frequent in order that real comradeship and friendships are developed amongst human beings, as well as the desire to support one another.

The catalysts to achieve the advances and positive results in the community are: people with disabilities and their families having leadership roles. Other catalysts are - working together at “comradeship” with all of those who are involved in the provision of community services, including professionals, friends, politicians, leaders, etc.; organize the services in a way that the existing economic and human resources are used in optimum way to the benefit of all.

There are a few basic elements, which have to be promoted in order to be able to get the community to support the integration of people with disabilities and to provide adequate and efficient services, which are of excellent quality:

X Promoting a culture which disseminates the equality of the rights for all human beings, as a basic principle so that all members of the community know that people with disabilities have the same rights as others do, due to the fact that they need to be a part of a society and it is our responsibility to provide excellent quality services with humanness and solidarity;

X Building of a more participatory community;

X Increasing the abilities of people with disabilities;

X Promoting interdependence between all human beings as equals;

X Uniting, creating and increasing the existing resources and to provoke a synergy when uniting more elements in their favour;

X Having planned and targeted activities, where the resources are focused at resolving common problems;

X Involving to the greatest extent possible, the members of the community in all matters having to do with the situation and services for people with disabilities;

X Increasing the confidence, in all members of the community, of all that can be achieved when we all decide to be “companions” of all human beings as equals;

X Improving the quality of life for all.

When the communities begin this process of development, all its members will discover how their own resources can have an impact in the lives of people with disabilities and they will try to unite to give strength to this change. It shouldn’t be forgotten that, within this struggle, we should work also for the benefit of those people with the greatest disabilities and not to discriminate in any way.

At least in some parts of the world, society’s attitude is changing and in large part due to our struggle. Some of these changes are important for bringing about an improvement, in the lives of people with disabilities:

X from community’s indifference to taking on a commitment on their part;

X from the solitude of people with disabilities to interdependence with all human beings;
X from segregation in isolated institutions of the society to a community life;
X from genocide to the celebration of the diversity of the human being and all of the corresponding riches;
X from charity to the rights for all human beings;
X from a culture of exclusion to one for life.

Family

Initially the family (and in particular the mother whom, innately and due to the love for her child, knows what to do even before the child is born) was in charge of "looking after the human being". From the moment of birth, in support of the family, the mother received help and advice. Members of the community also called on for their support.

When the behaviour of mothers in all cultures is analysed, we can see that the affectionate relations, which are established between mother and child from the very first moment are such that they provide the stimuli which the child needs in the various stages of his/her development. The mother does this naturally on account of the love which exists inside of her, without thinking that when she - cradles the child, she is stimulating the vertebrae which will helps to give a notion of movement and space; sings to the child, she is providing auditive stimuli; caresses and kisses the child, she is stimulating different sensory receptors in the skin; gets close, the olfactory organ is stimulated to permit the child to recognize the mother and to develop different areas and association between areas of the brain. Most importantly, these pleasant stimuli send a very valuable message to the baby's brain, the welcome the baby receives from the parents when it is born into the world.

Later the mother, through her daily games with the baby provides stimuli so that the child can begin to develop areas of the brain which are related to the speech, such as the imitation of sounds, syllables, words, areas for the understanding of language, of the association between language and images, support for the acquisition of walking, etc. In this way the mother, without knowing it, becomes the principal provider of "care and love" for the baby, as well as the first educator and teacher, with an ever growing love for the baby.

Nevertheless, when we speak of the relations, which exist between a mother and a child with a disability, we find that all this is presented differently from the start. The news of a disability in the child, causes a very strong emotional shock for the parents, especially when the person who communicates the news does so in a manner which is very abrupt, and negative, without having true knowledge of the human resources which can be brought to support this couple in crisis, nor of the community's resources which are so important to be used to support these parents in crisis, and of the possibilities for the development of the child and the child's right to belong to the society.

These professionals (who could be the general practitioner, the paediatrician, the nurse, etc.) are often also unaware of the advances which have been made in the areas of education, health services and the achievements which have been obtained to improve the quality of life of persons with disabilities. Nor will they think of all of the benefits that can be made available to the family on account of having a member with a disability who is respected, loved and which makes that family be a part of a common struggle for the well-being of that person. The integration of the family is produced and it is the basis of the disabled child's and family's well-being, as well a for the disabled child's future social integration.

During the first days of a disabled child's life, the mother cries, she is depressed, anxious, she denies what has been done to the baby, she feels cheated, she fights with her partner, the couple tries to blame one-another and often the disabled child is rejected. Sometimes this can be a transitory phase or it can last for an indefinite period of time. Sometimes just the acts of carrying and feeding the child is enough to feel love and this brings about a world of confusion in the mothers' feelings and attitudes.

Nevertheless, for the most part, the "welcoming into the world" is not offered to the same degree as with her other children. Those indispensable caresses, which will make the baby feel safe, protected and loved by his/her parents and belonging to the family and community, are not there.

From that day onwards, the development of the baby and his/her future will be intimately related to the maturation of the parents' emotions, which will be affected, particularly in the mother, by the initial abruptness or warmth with which the doctor informs the parents and by the attitude of indifference or "comradeship" of professionals. The quality of the health services at this time will be a basic determinant for the future of the whole family.

It is important to note that there are certain situations which can aggravate or help the situation for the mother, the baby and the family:

X The first news of the disability is given in an abrupt, rude and inhumane manner by the doctor, paediatrician, nurse, etc., thus provoking an emotional shock which often the parents are unable to recover from and may actually lead to the suicide of the mother, desertion by one of the parents, killing of the child through starvation, or institutionalisation to get rid of it; or,

X The first news is provided in a more caring manner, with good knowledge of everything that can be done to the benefit of the child, the importance of working together as a "team". The comradeship that can form between the specialists and the parents is such that the parents, if they are willing, can be trained so that they can be less tense and so be able to collaborate with the specialists. They are also informed of the resources, which are available to them from the community, of the support of families to families, etc. And it is pointed out, right from the beginning, that their child has the same rights as any other citizen and that they will have to be the defenders of those rights and to teach their child so that he/she is also able to defend those rights too.

X Many professionals are not well informed about the significance of the different alterations of the baby, the possibilities for the development of a child with disabilities, the existing resources in immediate and extended community. They don't have the proper knowledge to provide proper direction to the families and they are even less informed about the rights of that child and the advances, which have been made globally in this struggle for their rights. The result of their participation with the families will be destructive and will create more emotional instability for the parents, which will be reflected by the response that the family will have in the future of the disabled child. The relations will be cold, with little motivation on the part of the mother, while the disabled child will suffer from a lack of happiness and the stimuli, which are normally present between mother and child will be missing.

X There are no community resources, which permit the family to change their doctor or service and so they have to continue to put up with the destructive process provided by the doctor, nurse, social worker, etc. In many cases, this routine relationship will result in an environment which is lacking in love and stimuli during the development of the disabled child and where, as a consequence of inefficient services, segregation and marginalization are produced in his/her own habitat.

X There is no information about the community's resources, health services, schools, self-help groups, which can be freely consulted so that the family becomes more independent and feels it has many options, services and people in the community who can help. Or, there are no such services in existence for them.

X The family feels ashamed of having a child with a disability and it undervalues itself as well as the child. They accept what is presented without questioning whether the health or educational services were good or not, as the mother wants it to pass without notice. Nor is she able to demand quality services or something that is really relevant for the future of the child, because when they go to some health service or to the school, she only wants to return home as quickly as possible to hide her and her child away.

X The health services are of a bad quality and they don't cover the needs of the community. There is poor information and a bad organization of the public services, which results in that the families need to wait incessantly at the health services and the doctors do very rapid consultations. And this occurs due to the low esteem given to these families and their children. This may be because of lack of knowledge or lack of empathy, which is linked to the mentality of productivity, which makes these professionals think that they have no reason to be wasting their precious time on a child with a disability. This can reach the point that they may even refuse to conduct a critical operation to repair some malformation in the child's cardiovascular system. Sometimes the parents have to beg to them to accept their children in the different health and educational systems. Often they encounter refusals for the low esteem with which, they are held, including a lack of knowledge and empathy on the part of the professionals. Professionals don't take it as a personal and professional challenge to use their knowledge in order to get any child with a disability to be accepted, welcomed and to help him/her to progress. And their belief that such a child has the same rights as any other citizen, is even less.

X The families find specialists who have established in their lives a clear basis for the establishment of a market of technical services, which hold the promise of "fixing" children with disabilities. So they turn the anxious families into a source of enrichment, since the families try to get the money for periodic consultations, treatments and expensive medicines.

X The community and the professional and public officials, know of all of the information related to the emotional process which the parents go through. They know of all of the material and human resources, which are available to the community. They are well informed about different disabilities, medical resources and educational techniques, and they meet with the parents as "partners of the team" to inform them on the situation, what they can do, train them for better care of the baby, of what the community can offer them and the unconditional support that the parents can count on from them to resolve any situation of emergency or other consultation that they require, or to recommend them to others who can also help. In this way, an interdisciplinary work is begun amongst all of them and trying to make the painful emotional process of the

> beginning mature more quickly and with better consequences for the baby, the parents, the family and the community.

These different repercussions, with its good or bad consequences on the disabled child, the family and the community, continue to present themselves in the poor, as in the rich, countries. In the case of the poor countries, many errors have been committed due to a lack of understanding, interest and support by the society and governments, who have excluded and closed the doors of opportunity to people with disabilities. In rich countries, on account of the exclusionary practices that the society acted out on people with disabilities, by building large institutions where hundreds of people with disabilities were placed and distanced from the community.

Within this enormous social problem, there has been another group of parents throughout the World who have generated an nonconformity and ability to fight against the poor quality of life that their communities and countries, have offered to their children. They have demonstrated leadership and an energy without limits which is based in their infinite love for their disabled child who was seen, not as a third-class citizen, but rather as the loved child who needs the support of the family, and so achieve a change in their community. These parents began to create services for early stimulation, including rehabilitation and education. They studied, trained themselves, became united and went on to form social movements in all parts of the World. These were the origins of the special education schools, protected workshops, etc. The parents wanted to find the best resources in professionals who had the knowledge to develop the potential of their children.

Subsequently, the professionals began to doubt the capacity of the parents to provide services and so little-by-little the parents left the place to these professionals who were experts and apparently more able to do so.

Special education schools were created where a whole series of techniques were developed in order to make them more efficient, but at the same time the relations amongst people became robot-like, such that babies, children and youths with disabilities grew up in these cold conditions where there was a lack of commitment and where they were distanced from the society.

Later, due to the feelings of superiority of the professionals and the undervaluation of the families, instead of training them or providing them with incentives for the families to be in greater contact with their children, they separated the children and went on to develop the institutions, all the time getting larger and more distant from the city and so a whole different world was created which was separate from the community and, even more so, from the family. The result was that the children, youths or old aged didn’t have the right to be a part of the family and the community. Inside these institutions were committed the most horrible acts and thousands of children and youths grew up without any affective ties to their families or any other human being. In those institutions, it was possible to see eyes, which were empty of love and full of desperation on account of the lives that they were leading.

Some disabled people managed to get out of those institutions and spoke of what was going on in there, on account of a process of de-institutionalization which took place throughout the world, which still has not finished, but which at least has been able to get thousands of people out of that segregated world.

The errors which were committed, were analysed and now there is a movement, almost throughout the World, to: convert those services and make them more human; get them closer to the community and the families; provide the training and support that the family needs which would enable them to do things easier; and, to recognize the decisive role of the family for the welfare of the child.

At the same time, this movement is trying to disseminate the rights of human beings to take advantage of all of the services that the community has to offer, whenever it is necessary, which includes equality of opportunities for people with disabilities.

And also the obligations which the governments have to provide those services and make them at least of the same quality than for any other person and to implement those areas of support which are required for each disability. Always with the intention of trying to improve those conditions, especially in the case of developing countries.

Our time is one of change and re-evaluate the value of the human being, of families, the community and especially of the value of people with disabilities so that, together, we can build communities where interdependence and social justice, human rights, democracy and love will permit all human being to enjoy a fuller life.

Although these could be some of the aspirations of people with disabilities and their families, we know that at present, very few persons are achieving this throughout the World. So we should intensify the struggle so that their numbers will increase, with stronger and more important leaders, who can change the reality of the towns, with greater coalitions and coordination of resources which will permit that the services will be of better quality. To unite the efforts of different service institutions, with honest governments and solidarity, united in this same team.

II. Promotion of Values in the Society

How to Ensure the Responsibility of the State and Government Institutions in Development

Only by making the magnitude of this social problem of disability visible, shall we be able to get their voices to be heard and for actions to their benefit be taken. There are many millions of persons, who have joined the DPOs and we know that their numbers grow daily. At the same time unfortunately, the problem becomes more acute on account the problems associated with poverty, such as malnutrition, inadequate access to health services, poor hygiene, lack of education, social security, diseases of endemic or epidemic proportions, and the chaotic situations caused by alcoholism, drug addiction, conflicts, violence, environmental degradation, family problems, and social attitudes.

For these reasons, it is necessary and urgent to adopt strategies for the promotion of education, health and the well-being of those vulnerable groups, and to improve the systems for their attention and protection.

The union of people with different disabilities, the organizations of intellectually, visually and auditive disabled, as well as women’s organizations, old-aged organizations, organizations on different chronic illnesses, etc., will only be heard after they have constituted themselves as a true “social force”, with a well defined plan of development and a common vision.

These organizations should train themselves so that, together with their governments and specialists, they can form a framework and strategic plan for the revision, promotion and creation of new social policies and efficient systems of services based on what’s lacking or upon the existing needs of different groups, of which people with disabilities and their families are the experts to note what’s lacking and to evaluate the results of those plans and activities which should have direct repercussions in their quality of life.

Out of these unions will emerge many plans for collaboration amongst non-governmental organizations and governments. As well as the commitment to turn into reality those plans which were elaborated between them. The execution of those plans will increase the strength of these non-governmental organizations by making them more independent and analytical about the realities of their communities and country and the potential solutions to them.

That is why the formulation of social policies with the intervention of different groups of people with disabilities will represent the immediate interests of the different areas where changes are needed. Many of these changes will generate the need for the creation of new laws or to adapt existing ones.

This work should be based on the human rights of any person or group, regardless of whether or not they have some vulnerability and these people, in this way, instead of considering themselves as objects in need of compassion, will go on to be seen as people having all of the rights and privileges which, as citizens, should be heard and a response given to their needs. The mother, who for the first time confronts the reality of a child with a disability and has grown up in an environment in which she knows that all citizens of her country have the same rights will, from the beginning, be able to put up a fight more easily on the basis of the rights that her child has, without consideration to the degree of physical or mental limitations which they have, and will find those services she needs so that her child can develop adequately.

Within this process of the "establishment of partners" we find that, although the offering of services is a responsibility of the State, in order for those services to be provided with a better level of functioning and quality, the participation of different DPOs is required in order that they may be consulted, listened to and incorporated into the plans and evaluations which are made, such that the organizations representing special groups are given a more definite, active, budgetary and consultative role.

Within these changes there is the need, for people with disabilities as well as for their societies and governments, that a common vision for the future be shared for a "society for all", where well-being and community development form an important part. Where all members can be valued, respected and supported within their different cultures and relations, and where ethics in professional and daily activities of those services which will are provided are given a priority, as well as the solidarity which should be manifested at all times.

The international movement in favour of people with disabilities should be disseminated, within DPOs as well as through people who are not associated to an organization, in order that a cultural history can be formed of the achievements which have taken place in different countries through their Constitutions which, without question are a source of support for our struggle, as well as the international work of the UN which, through the Universal Declaration of human rights, establishes clearly the parameters of equality and social justice over the last fifty years, which subsequently was ratified in each of the Conventions, Declarations and International Years which the UN has held in favour of the most disadvantaged groups.

In 1993, the UN General Assembly reviewed a major document on human rights, titled "Standard Rules for Equalization of Opportunities for People with Disabilities". This document is a guide for all towns and was elaborated by the agencies, which form part of the UN, the Member States and the principal DPOs. In this document, all of the aspects, which need to be implemented in order to improve the lives of PWDs throughout the world are touched upon. For this reason it is necessary for PWDs and their representative organizations to know this work so that they may base themselves on it in order to demand a change of life and better services for them. This makes it necessary to form Partnerships with many members of society who can help to disseminate its information.

This will make the governments and communities more sensitive to the change that we should all give to the benefit of PWDs and to ensure that PWDs have the right to influence in social policies, programmes and decision processes, which will help them to have a descent way of living. It will also help governments to have the capacity to understand the social problem of disability and try to improve these conditions and, at the same time, to be more sensitive to the individual differences with particular needs and to try to support each citizen through a philosophy, for which all public servants should support, so that PWDs can live better as citizens of each country.

The role of the WHO can be decisive and a determinative so that, through means of its recommendations, meetings and regional coordinators, offer to all countries the changes which we want to be produced throughout the World with respect to the services offered to PWDs. The global influence of this organization could, without a doubt, influence to change not only the services, but also the attitudes of the whole society.

In the last few years, the developed countries have tried to distance themselves from the medical model, which was very dominating to PWDs. However, in this struggle they have reached extremes which can become detrimental for themselves such that, in some cases, they have even almost gone to the point of denying that many of them need support through the transition phase and, often, for life.

The recommendations of WHO will also be important to influence the national health norms which, especially in developing countries, are antiquated, obsolete, don't consider providing equality of opportunities to all PWDs and little less the right to health.

The establishment of new laws, which protect and defend PWDs isn't sufficient if the society, on account of its attitudes, doesn't promote them, doesn't develop social policies so that they are adhered to, with real strategies and initiatives. Nor will it be unless priorities are established about the issues associated with disability within the development plans and that the necessary resources be assigned so that these may pass on to becoming concrete activities to their benefit.

The establishment of National Plans for the development and integration of PWDs can be effective when, within the Coordinating Committees of these plans, PWDs and their families participate equally in the process of planning, implementation and evaluation.

Some of the National Plans have been elaborated while taking as a basis the Uniform Norms for the Equality of Opportunities, and so the participation of the government with DPOs becomes viable as a "necessary partnership".

Within all these changes which we are proposing, a New Vision is required for the 21st Century, which is based on respect and the right to life of all human beings. The starting point is that they all should have value, regardless of the circumstances.

The value of health, as the condition of well-being which corresponds to the promotion of an adequate quality of life within a community which values individual differences. To respect each human being which exists in the World and to also value the cultural differences which is present in each country and region.

The ethical and moral value of individual, professional, institutional and social action, as promoters of the change, as managers of the inputs to solutions within all existing problems

The value of individual and collective solidarity, as the generator of equality, social justice and well-being of people as well as "Partnership amongst human beings which generates interdependence in a World without frontiers and which belongs equally to all human beings".

I would like to add the Managua Declaration. It is a project, which was developed in America for a period of three years, with the participation of all countries, which are including representatives (a father of a person with a mental disability, a professional and a representative of the government). An analysis of the situation in each country was made in order to highlight common aspects of the physical, cultural and social barriers, which can impede that people with intellectual limitations to form a part of their society. Possible solutions were also analysed and a common vision was established which could unite all of our countries. It was a wonderful project which, although now finished, has continued to guide all of our work.

The Declaration of Managua

We want a society, which is based on equality, justice, equity and interdependence. Which ensures a better quality of life for all, without discrimination of any type. Which recognizes and accepts diversity as a fundamental aspect of community living. A society where the condition of each of member comes first: which guarantees their dignity, their rights, their auto-determination, their contribution to a community life and their full access to social welfare.

Let’s recall that we have the obligation, within societies and governments, to ensure the participation of PWDs and their families in the formulation of legislation and coordinated policies, in order to achieve this ideal.

Furthermore, we commit ourselves to the development of policies which support social integration according to the characteristics of the community in which the child or youth lives, through the provision of information and orientation to the family, as well as making possible the implementation of labour policies and not limiting migration.

The signatories and the institutions represented, will work in favour of the concrete objectives which we have identified and will participate: to the elaboration of governmental policy, legislation; in the promotion and defence of rights; to the establishment of associations and forms of cooperation; to the awakening of the public conscience about these issues; to develop information and research systems; and guaranteeing the support and necessary services.

Signed in Managua, Nicaragua on the 3 December 1993. UN International Day of Disabled Persons.

Discussion Paper Prepared by

Dr. Garé Fabila de Zaldo

REDEFINING CARE: Building Bridges from the Medical Model to the Social Model: A Taxonomy of Discourse: Rethinking the “Care” Rehabilitation Model, *Richard (Sal) Salcido*

BACKGROUND:

The last two decades of the 20th century started with the celebration of the international year of disabled persons. This tribute opened the approach for a long and profound examination of rehabilitation service delivery models. In the intervening two decades, there has been a significant change in societal norms, values and expectations. The world is a much smaller place than 1981, when we celebrated and memorialised the need to examine the uniqueness of the disabled population, while at the same time acknowledging their special needs, wants and aspirations. The contraction of the world in various sectors, especially in communications, is phenomenal - the ability of an individual or an organisation to communicate with the world in seconds is not only common place it is expected. Nations once divided are working together to solve problems, more commonly in business relationships and episodically in public health crisis.

These new social paradigms, to be of value, must be applied to all segments of society including the disabled. As rehabilitation specialists, we must understand the customers we serve, their wants, needs and expectations. As persons with disabilities participate in the new world order, we can expect challenges to old models. Medical models that promise more than they can deliver, will no doubt be at odds with those expecting more services than they get. The time has come to develop a global view of rehabilitation services delivery by involving relevant stakeholders, especially the sector representing the disabled population, Non Governmental Organisations (NGO), Disabled Persons Organisations (DPO) and Persons with Disabilities (PWD). This appeal must extend to governmental agencies, thought and content leaders in the field, and providers of current medical models.

Introduction:

The purpose of this paper is to re-examine and analyse the concept of “care”, as it pertains to the delivery of rehabilitation services to persons with disabilities. The views outlined are from the perspective of a specialist, in the field of rehabilitation medicine and are in alignment with the concept of Community Based Rehabilitation (CBR). Currently, there exist two main models of rehabilitation service delivery. The most common and well know model is the “Medical Model” of rehabilitation (MMR), from the medical point of view, this is known as the acute and post- acute rehabilitation model. This model of care is most prevalent in countries with highly developed medical care and health care delivery systems. In the MMR most of the recipients of rehabilitation care are recovering from some acute physical impairment or catastrophic illness, such as a stroke, acute spinal injury, traumatic brain injury or other recently acquired disabling condition. In the MMR model, a multidisciplinary team of specialists works in concert to enable the “patient” to reach maximal medical improvement and to achieve maximal functional and physical performance. Reaching the stated goals greatly depend on the factors of the physical impairment, disability and handicap and the underlying medical illness or co-morbid conditions. Success also depends on availability of the services. The major thrust and result of the physical rehabilitation effort in the MMR is to fully integrate or reintegrate PWD into the community. In MMR, the acute care patient is the recipient of a medical paradigm of care. In contrast, the "Social Model" is often referred to as the "post-acute-period" by the medical establishment. This period requires less "medical intervention" and the "patient" may increasingly rely on social support systems, such as family and community. In contrast, PWD may refer to the social model as a system with more independence and separate form medical oversight and supervision. The " Social Model" is used mainly in the psychiatric and mental health literature. This model was popularised when certain psychiatric diagnosis became manageable in the community because of the introduction of novel pharmacological agents, allowing patients to be safely treated in the community with out hospitalisation. At the same time human rights, issues precluded a model of psychiatric hospitalisation or unwanted incarceration for patients who were at no risk for harming themselves or others. The human rights movement identified the lack of self-determination for the persons "cared" for in institutional psychiatric settings. This example is about a major transformation in social policy, which resulted in the de-institutionalisation and demedicalization of psychiatric and mental health services.

While there are those who compare the demedicalization of mental health to the need to demedicalize rehabilitation services, there remains a paucity of literature describing the social model of rehabilitation. The origins of the social model of rehabilitation are directly linked to the disability movement. The disability advocacy movement began in the 1970's and developed because of dissatisfaction with the perceived medical philosophy and treatment of persons with disability. A major thrust of concern for DPO's, is that the medical establishment defaults to the disease model in all interactions with them and tend to treat PWD as "diseased persons", placing or categorising them into some medical classification scheme. Disability rights activists are critical of the "Medical Model" and are reticent to develop alliances with the health care industry. The disability movement rejects the commonly held belief that PWD, are victims of their physical impairment, but strongly asserted that society is handicapping PWD, by creating barriers to their independence. As a result, several important themes or appraisals describing the current model of rehabilitation care emerge; Questions to be answered:

  - Does the Medical Model focus on only one dimension of a tripartite classification system designed to incorporate?
  - Body functions and structure.
  - Activities at the individual level.
  - Participation in society.
  - Does the current Rehabilitation Model stop short of achieving the desired outcome? Full community integration for PWD?

- Is the view by the DPO and PWD that the Social Model, is the only facet in achieving overall quality of life and full independence?

- Do rehabilitation physicians view the need for an alliance between the medical model and the Social Models, and is the Medical Model an old paradigm?

GOALS:

1. Determine the preferred taxonomy of discourse, how we communicate about these issues.

2. Definition of a provider based Medical Model for rehabilitation.

3. Definition of community based, client centered (social) rehabilitation model.

4. Develop a transformation (hybrid) model based on the needs of the persons served.

Models:

There currently exist diverging models- the Medical Model and the Social Model. I will attempt to describe the detachment of these two models and the opportunity that we have as physicians to bridge these dynamic models.

Figure 1 THE CREATIVE TENSION: DIVERGING MODELS of REHABILTATION

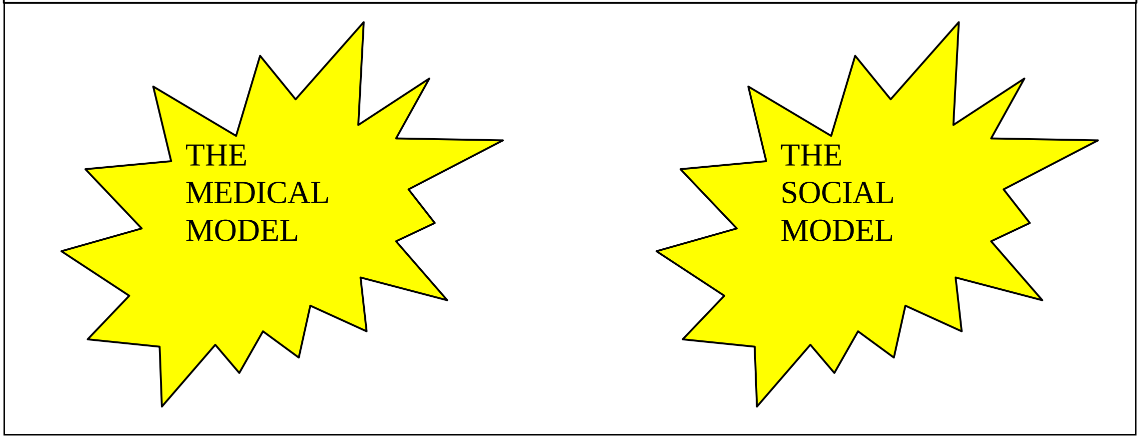
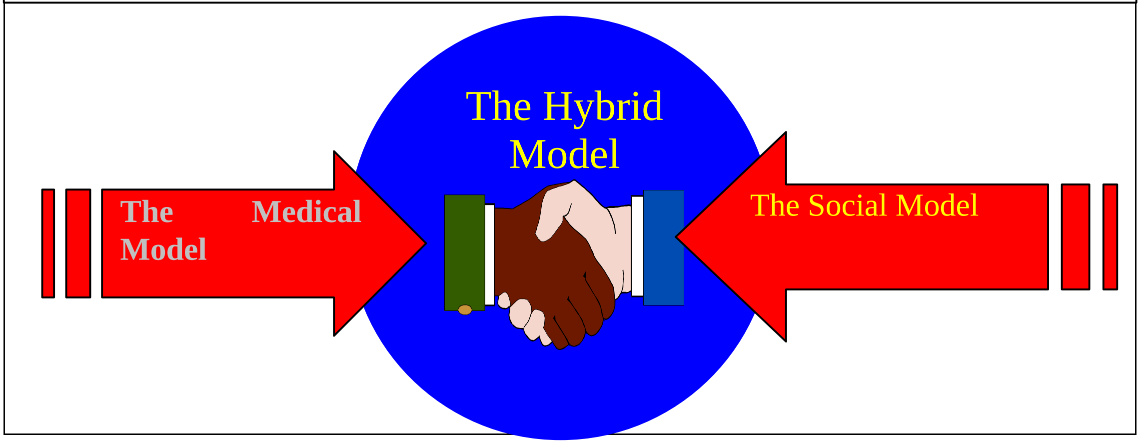


Figure two THE MERGING OF THE TWO MODELS:



What is The Right Model?

The "Pure Medical Model" utilized in the traditional provider patient relationship is currently under challenge and may have less utility for a variety of reasons. In an ever changing world. In the New World, the sophisticated recipients of rehabilitation management services (RMS) are challenging current models of Rehabilitation Medicine Service Delivery. Especially those that are viewed as paternalistic (top down) (pupulin). In a study looking at who was more likley to receive rehabilitative care in the United States, it was shown that those with the most resources and those who were more sophisticated received the most rehabilitation (Haystings). On the other hand, less able recipients of RMS and those in less developed environments, may default to the survival mode and be less concerned with a medical model they have no history of accessing. They may want or need to focus mainly on functional restoration, for pure survival. There in lies the conflict, the medical model is an old paradigm and is inherently in constant dynamic tension between those that view RMS as a medical model and those that view RMS as a social model. Persons with physical impairments, disabilities and handicaps may have acquired a condition or co-conditions that require episodic medical treatment; similar to able bodied (non-disabled persons). In the case of the non-disabled person, access and utilization of medical care is a self-directed activity and is considered a choice. However, persons with disabilities may be required to have a directed medically supervised intervention even when they would rather choose an alternate strategy. It is the case, however, that persons with disabilities will at times choose access both rehabilitation services as well as medical services throughout their lives. Having the choice, and the ability to access medical services, remains an important aspect of the total well being of any person including those with disabling conditions. Persons with disabling conditions should be able to default to the (non-medical) social model when indicated. To successfully participate in discourse about the concepts outlined-we must define them. What is care in relation to the social model and what is care from the perspective of the medical professional?

Taxonomy

In the scientific sense taxonomy is a method of classification, nomencalture (naming) categorising, cataloguing, arranging and organizing a given biological or clinical model. An example of this, is the International Classification of Diseases (ICD) by the World Health Organization. These classification models are based on the principle of taxonomy or classification. In some cases there exist international consensus about the nomencalture of specific problems, for example the ICD classification and naming for amputation of limbs, based on the specific type, level and reason for amputation e.g. congenital, traumatic or surgical. It is through this mechanism, we are able engage in discourse (communication) based on a common language. A common technical language, no matter the purpose allows a given field to advance. The uses of appropriate descriptors for the various models of rehabilitative care from the perspective of a medical provider and for the persons with disabilities, which we evaluate and treat, are important. If we are to move the field forward and communicate effectively amongst rehabilitation professionals, policy makers, researchers and patients we should take our method of communication seriously. A common rehabilitation language facilitates communication with rehabilitation professionals and PWD through out the world. The practice of rehabilitation is moving from a pure medical model to a recognized social model of care and how we engage in the discourse about this change is important.

The Discourse

Many opportunities exist to examine the language of rehabilitation and the concept. The term rehabilitation from the medical sense is a model based on a pathology model (after a problem develops) on the other hand, the term “social model” allows for the conceptual framework of prevention health and well being. DPO: Disabled Persons Organisation interested in the general topic of rehabilitation use a variety of nomenclatures to differentiate themselves, perhaps for historical reasons or to respond to a market base. This practice insures competition amongst differing groups interested in the various models. We must find ways of collaborating across these groups especially when it comes to defining the overall concept of rehabilitation. Using appropriate definitions and modifying our terminology over time allows the field to adapt to the changing models of care. We reach far beyond our own specific interest in rehabilitation, whether it is the Medical Model, Social Model or a self directed program.

Is the term care still appropriate?

The word “care” in the medical and nursing model implies that the patient is a passive recipient of a prescribed treatment. In the social model, the client is “empowered” and the practitioner is in more of a consultative role or a teacher (physician). It is clear that at times the practice of care is both a Medical Model and a Social Model. Since these models are evolving, it gives us pause to rethink the meaning of "care" (O'Hagen). In The thesaurus, the word "care" is defined as to mind, be bothered, be concerned, worry, think about and heed. As a noun, care can mean custody. The term custody means to supervise, charge, control, guardianship and to protect. In the pure medical model these terms are paternalistic and do not include the patient as a collaborator in helping to solve the particular problem at hand.

Attendees of a recent conference heard Jill Kilmont-Booth (an Olympic skier) describe her experiences as a person with disabilities, including the experience of pressure ulcers requiring surgical intervention. She further described to us, how she assumed the responsibility for herself, as much as possibly living a full life. Once she self empowered to evaluate her own risk for pressure ulcers and to recognise when to seek appropriate consultation from knowledgeable clinicians. In her case, the term care did not take into account the responsibility nor need the patient had to participate in the expected outcome.

Currently, as a visitor to the World Health Care Organization in Geneva, Switzerland, I am participating in a "rethinking process" related to the concept of care in persons with disabilities. This work is in preparation for a global conference on rethinking care in Oslo, Norway in the year 2000. The purpose of this effort is to involve the disabled community in a process whereby they participate in defining care, based on their needs and set the stage for international debate on the subject. This project has stimulated my rethinking as appropriate to the field of medical rehabilitation.

Summary

As rehabilitation professionals, we need to communicate more effectively about rehabilitation by using more precise terms to describe the specific types and concepts in rehabilitation. We must accept the challenge before us. The rehabilitation community should develop consensus as to the naming and classification of rehabilitation. We must rethink the way we communicate with each other about rehabilitation and take the opportunity to redefine care and blend the medical and social model to achieve a partnership with the persons being served. We can no longer treat the problem using a pure medical model, therefore, we must enter a partnership with the person served and evaluate and treat the whole person.

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TERMINOLOGY

DAR; Disability and Rehabilitation is a cross cluster initiative with in the World Health Organization (WHO) with in the Management of Non Communicable Disease cluster
NGO: non-governmental Organisation
DPO: Disabled Persons Organisation
PWD: Persons with Disabilities

RE-THINKING CARE FOR PERSONS WITH DISABILITIES: A VISION FOR NURSING, *Dr. Dena Hassouneh-Phillips & Dr. Mary Ann Curry*

The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (March, 14, 2000) were developed to promote full participation and equality in society for persons with disabilities worldwide. Full participation and equality will exist when persons with disabilities have equal rights and access to the same opportunities as all others. Working toward these goals requires attention to the contexts in which persons with disabilities live and the development of strategies for change.

Nurses, as professionals who provide care to persons with disabilities in all nations and in various settings, are a key group of professionals that can make a difference in the lives of persons with disabilities. To promote positive change we must challenge old ways of thinking among nurses and introduce new models of care that encourage persons with disabilities to empower themselves. This movement requires no less than re-thinking nursing care for persons with disabilities across the globe.

This paper is an effort to take on the task of re-thinking nursings' role in caring for persons with disabilities as we move toward the goals of full participation and equality. Central to this task is learning from persons with disabilities themselves what their nursing care should look like. Nurses are often unaware of aspects of their practice that are perceived by persons with disabilities as disempowering and hurtful. As a consequence, our image in the disability community is not always a positive one. Improving our nursing practice requires that we listen and respond to criticism and solicit recommendations for change from the people we serve. As we listen to and learn from persons with disabilities we will begin moving toward a collaborative practice. First and foremost nurses must collaborate with persons with disabilities, since it is they who possess the expert knowledge we need to change our practice.

Central to our vision for a collaborative practice is support for the movement toward self-directed care that is occurring in many countries. Having said that, we recognize that self-directed care may not be consistent with the values of some group-oriented cultures. In addition to group-orientation, gender role socialization is another cultural difference that can profoundly influence nursing care for persons with disabilities. In some regions, female nurses may be limited by social convention in their ability to travel and practice independently. Consequently, the recommendations set forth in this paper cannot be uniformly applied to all nursing contexts. It is beyond the scope of any single paper to address the multiplicity of cultural contexts of disability and health across the globe and therefore we have not attempted to do so. Instead, we offer a more general vision for nursing care of persons with disabilities and hope that this paper will serve as a springboard for discussion both within and across cultural groups.

As we endeavor to re-think nursing care for persons with disabilities we begin by outlining a series of assumptions about disability and nursing practice. This is followed by a brief discussion of important contextual issues (contexts) in the area of disability and health. Important contexts include: human rights and violence; vulnerability of women and girls; and inadequate access to health care, education and employment. Each of these contexts is then considered as they relate to the four areas that have been identified by the United Nations as essential preconditions for full participation and equality of persons with disabilities in society. Having made recommendations for change, we then conclude by critically examining barriers to change and considering ways to overcome them.

DISABILITY AND NURSING PRACTICE: GUIDING ASSUMPTIONS

Persons with disabilities are a large, diverse, and growing population who comprise 10 percent of the people in the world. Among the global population of persons with disabilities, 2/3 live in developing countries, 80% live in isolated rural areas, and the vast majority live in poverty. When examining disability within the contexts of nation, locale, and income level, differences in gender, ethnicity, religion, and disability-type also emerge. Hence, it is clear that diversity among the global population of persons with disabilities is far-reaching and powerfully influences the meaning of disability for people in everyday life. In fact, the very notion of disability itself differs dramatically across cultures making the task of re-thinking nursing care from a global perspective very complex. As previously noted, it is not possible to address the multiple and complex cultural issues relevant to disability and health in one paper. However, it is equally impossible to re-think nursing care from a global perspective without addressing these issues at some level. Thus, to clarify our vision we have formulated two assumptions about disability and society to ground our efforts at re-thinking nursing care for persons with disabilities in diverse societal contexts.

First, we have chosen to define the concept of disability itself broadly, incorporating physical, sensory, cognitive, psychiatric, and social aspects of disability for the purposes of this paper. It is clear that this comprehensive definition is not consistent with the variety of definitions that exist across cultures. Nonetheless, we have deliberately chosen a definition broad enough to ensure that the scope of this paper encompasses the variety of groups who are affected by disability worldwide.

Second, is the assertion that persons with disabilities experience different kinds of social vulnerability. Socially constructed human categories that discriminate such as gender, disability-type, race, ethnicity, class, sexual orientation, and age, place persons with disabilities at different levels in existing social structures. These qualitatively different levels have significant implications for the health and well-being of many sub-populations of persons with disabilities. Understanding this reality is essential to understanding the contexts of disability and health discussed throughout this paper.

CONTEXTS THAT INFLUENCE THE HEALTH OF PERSONS WITH DISABILITIES

As we re-think nursing care, it is essential that we consider contextual issues that significantly influence the health of persons with disabilities. Based on our review of the disability literature, we believe that the following contexts significantly shape the health of persons with disabilities worldwide.

Human Rights and Violence

While the issue of human rights and violence are relevant to all persons with disabilities, women and girls often bear the greatest burden of this problem. Internationally, women with disabilities have identified the high rates of violence against women and girls with disabilities as a critical health and human rights issue (Berkeley Planning Associates, 1996; Economic and Social Commission for Asia and the Pacific, 1995; International Leadership Forum for Women with Disabilities, 1997; Nosek, Howland, Rintala, Young, & Chanpong, 1997). They have also called attention to the strong links between poverty, violence, and disability.

Violence is too often the cause of disability. While obvious examples are the terrible physical and emotional injuries caused by war, other forms of violence can also result in disability. Examples include traumatic brain injury as a result of repeated blows to the head, fractured limbs, female circumcision, and post-traumatic stress disorder from exposure to violence. People with disabilities as a whole are also at greater risk for experiencing abuse from family members, paid and volunteer care providers, institutional staff, police, health and social service providers and society. Acts of violence perpetrated by care providers include humiliation; rape; neglect; isolation; withholding of assistance, equipment and medication; physical assault; abandonment; being put out to beg; slavery and murder. In addition, it is important to note that the disabled children of non-disabled battered women are particularly vulnerable to abuse. These children are at increased risk for witnessing violence in the home, and are all too often the targets of physical and sexual violence themselves.

Nursing has a professional obligation to address these human rights violations. At the most basic level, nursing must take an active role in violence prevention. In war-torn areas, nursing must work to ensure that persons with disabilities have access to quality field-based health services and follow-up care. We need to systematically assess, intervene, and document the extent of violence against persons with disabilities overall, and against women with disabilities in particular. This assessment should be broad in scope and take place in all settings.

Vulnerability of Women and Girls

Closely linked to women and girls' vulnerability to violence and abuse is the discrimination experienced by women with disabilities who are also poor. Because of the powerful and pervasive effects of systems of oppression, these three aspects of human identity, when combined, have been termed by many disability scholars as *triple jeopardy*.

Women with disabilities who are poor are among those most at risk for being isolated and marginalized within their communities (Economic and Social Commission for Asia and the Pacific, 1995). This discrimination frequently begins at birth. In many cultures, girls who are born with disabilities are more likely to be killed or left to die. If a girl who is disabled survives, she will probably have less access to health care, education, and employment, and is likely to be excluded from normal social roles such as wife and mother. This discrimination creates and exacerbates poverty, which in turn places women with disabilities at increased risk for abuse and neglect. This risk is particularly high among women living in poor, less developed, and rural areas since these areas often lack access to information, services, and resources.

We make this point because it is critical for nursing to recognize that it is discriminatory social institutions that are the root of the problem and to understand that individuals with disabilities, and women in particular, are not passive victims of oppression. As we consider the significance of systems of oppression in the lives of persons with disabilities we must also begin to consider the ways in which we as individuals, and members of society, contribute to this oppression. Perhaps our greatest challenge in re-thinking nursing care for persons with disabilities is the need to critically examine our own social privilege as we work to end systems of oppression.

Inadequate Access to Health Care

The Consensus Statement from the International Leadership Forum for Women with Disabilities (1997) addresses the problem of inadequate access to health care for women with disabilities and makes recommendations to close this gap. While the Forum specifically addresses women, the issues they summarize are also relevant to men with disabilities:

> "Because of the discrimination and ignorance of medical professionals and extreme poverty, women with disabilities do not have the same access and opportunities for health care as their able-bodied counterparts. The power of health care professionals, particularly in mental health and developmental disabilities arenas, will not be given up easily. Disabled women are dying prematurely as a result of not getting the care we need. Disabled women do not receive adequate personal assistance, assistive technology and supports because of lack of funds" (p. 9).

The Leadership Forum demanded that National health policies and bureaucracies be accountable for improving the access, availability, and affordability of high quality, culturally competent health care for women and girls with disabilities and for insuring that rehabilitation services are available to them without gender bias. In addition, the Leadership Forum identified the need for persons with disabilities to be trained as leaders in research on women's health care needs and the need to evaluate the outcomes of medical procedures from the point of view of the population served. Likewise, the need to provide adequate reproductive health care, including education by and for women with disabilities, was identified as a high priority.

Nursing should and can be an active partner in achieving these goals. To do so, however, nursing will need to become more diverse and knowledgeable. Active recruitment of students with disabilities into nursing programs and critical examination of existing curricula for content related to disability must occur. These changes must include recognition that people with disabilities are the experts regarding their health care needs and should be an active partner in developing the curricula. This will require that we fundamentally shift the focus from a nursing-driven model to a collaborative model that supports the self-empowerment of people with disabilities. In essence, we must advocate for this re-definition of power not only within nursing, but also across all health and social service systems.

Inadequate Educational and Employment Opportunities

Access to education and employment is critical for people with disabilities, especially for women and girls who receive less education and are employed at lower levels than their male counterparts with disabilities. It is important to recognize the significance of education and employment for persons with disabilities as primary tools for fighting poverty, social exclusion, and inadequate access to health care. The International Council of Nurses (ICN) position paper on Poverty and Health and the Girl Child (2000) firmly established nursing's role in addressing educational and employment disparities. We must use the knowledge we gain from working with individuals and families to advocate for system-wide improvements in education and employment for persons with disabilities. Because we practice in a variety of settings and work with many other professionals, nurses are in a unique position to identify and articulate the links between lack of education and employment and the health and social status of persons with disabilities. We have a responsibility to end this discrimination.

FOUR PRECONDITIONS FOR FULL PARTICIPATION AND EQUALITY OF PERSONS WITH DISABILTIES IN SOCIETY

The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (March 14, 2000) outline four preconditions for full participation and equality of persons with disabilities in society. Discussion of the four preconditions allows us to consider ways that nursing can re-think practice within systems while at the same time addressing each of the key contexts described above.

Awareness-Raising

Raising awareness about the rights, needs, and contributions of persons with disabilities in society is vital. This task is the foundation upon which all other efforts to ensure full participation and equality for persons with disabilities in society rest. Nurses, as care providers who exist in all cultures, are uniquely positioned to address this issue in ways that are culturally competent and effective. To do so, however, requires that nurses re-think their traditional nursing roles in all contexts and across specialties. This provides the opportunity to take on the roles of activist, advocate, policy-maker, coordinator and educator for the purpose of challenge existing assumptions about disability in society.

Activism

In our roles as disability activists, nurses must systematically work toward increased recognition of the contexts of disability and health previously described: human rights violations, violence, discrimination, and inadequate access to health care, education, and employment. This kind of activism requires that we become information gatherers in our local communities. Assessment of current conditions in our own communities can provide the information required to advocate for needed services. Information gathering is particularly vital in isolated rural areas that often go without even the most basic of services. Examples of the kinds of information that nurses can gather include stories of violence and abuse, its prevalence, current rates of employment and educational levels, and lack of access to basic health care among persons with disabilities in local settings.

Advocacy

As disability advocates, nurses must find ways to combat violence and discrimination against persons with disabilities. Using the example of abuse, we can see the urgent need for advocacy in health care, social, and legal systems. In many instances the abuse experienced by persons with disabilities is either ignored or goes unrecognized. Even when abuse is identified, stereotyping of persons with disabilities as individuals who do not have the right and/or ability to make decisions about their own lives often prevents appropriate responses. Nurses have a responsibility to ensure that abuse is taken seriously and action taken. This may mean re-thinking traditional ideas of what constitutes nursing care to include actions such as going with a victim of abuse to court, or challenging co-workers who want to blame victims for staying with their abusers. It also includes raising awareness about the significance of abuse for people with disabilities among family members, health and social service professionals, the police, the courts, and governmental and non-governmental (NGO's) organizations. Similar advocacy roles are needed in the areas of discrimination against women and girls, access to health care, education and employment.

Influencing Policy

Working with the disability community, nursing has a responsibility to increase the awareness of policy-makers regarding the need to include the perspective of the disability community on health and public policy. The United Nations World Programme of Action Concerning Disabled Persons (10/19/2000) is an excellent guide for nurses to use in this endeavor as they make sure that critical issues such as abuse, discrimination against women and girls, and inadequate access to health care, education, and employment among people with disabilities are addressed in the policy arena. At the community level, this may mean working with the local school district to improve access to education for children with *disabilities or instituting a program of universal screening for abuse at the hospital. At the regional level it may mean organizing support for an accessible transportation service. And finally, at the national level, efforts to influence policy might include advocating for improved access to primary health care or improved funding for disability services.*

Educators

Finally, the role of nurses as educators has tremendous potential to increase awareness of the needs, rights, and potential contributions of persons with disabilities in society. In partnership with persons with disabilities, nurses must educate the public, professionals from a variety of fields (including nursing), local volunteers, and employers. In addition, as coordinators of care, nurses have the opportunity to partner with schools, health centers, NGO's, and other organizations to promote awareness of what programs and services are currently available and needed for persons with disabilities and their families. This information should be targeted at both service providers and persons with disabilities to foster collaboration across groups. Given that 80 percent of all persons with disabilities live in isolated rural areas in developing nations where the rates of disability are highest, efforts to reach rural areas should be given the highest priority.

The kind of awareness-raising by nursing we propose is perhaps best understood within the context of a real life example. Catherine Phiri is a nurse who recently received the Race Against Poverty Award for her work in raising awareness about HIV/AIDS in her home of Malawi. Nurse Phiri has seen many loved ones die of AIDS and is herself HIV positive. Watching the devastation of AIDS spread across her country, nurse Phiri founded a support group for people who are suffering not just from HIV/AIDS but also from the neglect of a society uneducated about the illness. Her organization offers testing, counseling, education, and moral support for persons with HIV/AIDS and their families. In addition to providing services, nurse Phiri has also sent multiple proposals to government officials and policy-makers in her efforts to raise-awareness and garner support. Nurse Phiri's work addresses an important health issue within the context of her own culture at the grass roots level. Her work exemplifies the model of nursing practice we advocate.

Medical Care

Re-thinking nursing care for persons with disabilities in health care systems requires attention to four areas: 1) prevention of disabilities; 2) health promotion and health maintenance for persons with disabilities; 3) reproductive health care; and 4) acute and long term care.

Prevention

Prevention of disabilities is a subject that quickly draws attention to the economic inequality that exists across and within nations. Clean water, sanitation, adequate nutrition, access to health care and medicines, and immunizations are basic public health needs that remain unmet for much of the global population. Also of concern is the epidemic problem of unintentional and intentional injuries. Preventing unintentional injuries requires that governments and employers begin to identify and eliminate occupational hazards in the work place. Educating employers and legislators about ways to reduce workplace injuries is a task that nursing must be willing to take on. With regard to intentional injuries, it is clear that nursing as a profession must advocate non-violence. As previously noted, the number of persons affected by violence, abuse, and war worldwide is both heartbreaking and staggering. Addressing these issues requires an international nursing presence that is both vocal and untiring in its efforts.

Health Promotion

Health promotion and health maintenance for persons with disabilities is an area that has been long neglected in even the most sophisticated and affluent of health care settings. Too often, the attention of health care providers is focused entirely on a person's disability. As a result consideration and discussion of preventative health care and health maintenance activities often never occurs. Other barriers to preventative care for persons with disabilities include negative stereotyping and/or abuse by health care workers, physical inaccessibility, and lack of health care resources.

Stereotyping

Stereotyping of persons with disabilities is a substantial barrier to providing preventative health care to persons with disabilities. Challenging this stereotyping requires that nurses critically examine their own attitudes toward persons with disabilities. This means moving away from the (medical) model which views disability as a defect needing to be cured, to a model that promotes acceptance of persons with disabilities in society. Until this transition occurs, nursing care of persons with disabilities has the potential to be harmful rather than helpful. This change requires teaching nursing students about disability issues and offering continuing education to nurses in practice. When all nurses and other health care providers begin to view people with disabilities as *whole* people who are survivors of disabling conditions rather than as victims of polio, multiple sclerosis, spinal cord injuries, etc…health care for persons with disabilities will have taken a major step in the right direction.

Violence and Abuse

The problem of violence and abuse of persons with disabilities previously described, is not restricted to personal assistance providers, domestic partners, and family members. Tragically, persons with disabilities are also abused by health care providers, including nurses. There are intentional forms of abuse and neglect that are obviously harmful and should never be tolerated. However, there are other types of abuse that health professionals may not even realize they are guilty of committing. Nursing should assume leadership in learning from people with disabilities these types of behaviors that are commonly experienced as abusive. For example, our research indicates that behaviors, such as not providing adequate pain relief, not giving a person time to explain their situation, and pushing someone beyond their limits, are perceived by persons with disabilities as very hurtful regardless of whether or not they were intended to be abusive. These behaviors then need to be included in standards of care that address the problem of abuse of persons with disabilities in health care settings.

Physical Access

Physical access to health care facilities is another major barrier to preventative health care for persons with disabilities. When physically accessing health care facilities is difficult, health care visits may be limited to urgent problems. In many areas roads are unpaved, there is no public transportation, and the nearest health care facilities are very far away. Clearly, economic development of nations must go hand in hand with providing adequate medical care to persons with disabilities. Until this occurs, issues surrounding physical access will continue to be a problem.

Health promotion for persons with disabilities should be identical to the standard of care that exists for all persons in their local communities. We recognize that this will vary dramatically across countries, and may range from annual health maintenance exams that include, cervical, breast, and colon cancer screenings to a focus on sanitation, adequate nutrition, and immunization. Regardless of what the standard is, nursing must advocate for equal access to health promotion for persons with disabilities across all health care settings. According to a North American disability activist (Nosek, 2000), "to talk about wellness in the context of disability is to break the strangle hold the medical model has had on disability interventions for far too long" (p. 136). Focusing on wellness in the context of disability is an absolutely essential task for nursing as we re-think our practice.

Reproductive Health Care

We identified discrimination against women and girls as an important context of disability and health that should be addressed by nursing. Perhaps nowhere is this discrimination as prominent as it is in the area of reproductive health care. There is an unfortunate stereotype in many cultures that women and teenaged girls with physical disabilities are not sexually active, and conversely, that those with cognitive disabilities are overly sexual. These stereotypes carries over into medical and nursing school curricula, leaving health care providers ill-equipped to counsel women and teenaged girls with disabilities as they make decisions about contraception, pregnancy, prevention of osteoporosis, and hormone replacement therapy.

> *Education of physicians and nurses working in the area of reproductive health care must include appropriate and accurate information about women with disabilities. Recognition that women and teenaged girls with disabilities have the same need for reproductive health care as all other women and teenaged girls must come first. From this recognition follows additional considerations about how disability influences, if at all, reproductive choices and health care for women and teenaged girls with disabilities. For example, a woman with a spinal cord injury should be treated first like all other woman of reproductive age, and second as a woman with a disabling condition. This means that standard women's health care measures such as cervical cancer screening, breast exams, discussion of birth control and sexually transmitted disease etc., should consistently be provided. After these standard women's health care measures have been provided, then the implications, if any, of this woman's spinal cord injury on reproduction can be considered. Once educated about disability and reproductive health care themselves, nurses can then begin to educate many of the lay volunteers who are active in their local communities. These activities should improve the quality of reproductive care for women and teenaged girls with disabilities overall, and expand available reproductive services in remote settings.*

Acute and Long Term Care

When considering acute and long-term care for persons with disabilities it is important again to recognize that huge disparities in access to services exist across nations. In many nations, the bulk of funding for acute and long-term care for persons with disabilities goes into funding a few specialized centers – centers that the majority of persons with disabilities cannot access. While specialized centers of care have their place in providing medical care to persons with disabilities, they are not and cannot ever be, sufficient to provide care to all persons with disabilities. In response to this dilemma, nurses must become prepared to provide care to persons with disabilities in their local communities. This will require that nurses receive advanced training in providing health care services to persons with disabilities. In collaboration with existing community-based organizations, nurses have the potential to radically expand access to health care for persons with disabilities. This is particularly true in rural areas where nurses may be the primary source of acute and long-term care services and family education in the care of their loved-ones. A model to consider for the future is the Rehabilitation Nurse Practitioner Role developed in the United States. These nurses have advanced training that prepares them to diagnose, treat, and prescribe medications for persons with disabilities. The practice of these nurses has been consistently proven to be high quality, safe, and equivalent to physician care on all measures.

In summary, medical care for persons with disabilities can change by re-thinking nursing care. Nurses must advocate for the same standard of health care available to persons without disabilities and maintain a focus on health promotion and access to reproductive health care. In addition, nurses practicing in acute and long-term care facilities needs to promote self-directed care. By partnering with persons with disabilities, NGO's, other professionals, and government organizations, nurses can play an important role in increasing access to and the quality of health care for services for persons with disabilities.

Rehabilitation

The United Nations (March 14, 2000) defines rehabilitation broadly to include early detection, diagnosis, and intervention; medical care; social, psychological and other types of counseling; training in self-care activities; provision of technical and mobility aids and other devices; specialized education services; vocational rehabilitation; and follow-up of all of the above. This broad and inclusive definition of rehabilitation can provide a vision for nursing as we re-think our roles in rehabilitation services. Given the broad definition of rehabilitation stated above, it is very likely that nursing has already been involved in some aspect of most every disabled person's rehabilitation. A community nurse may be the home health visitor that helps to organize support for a family member who has just returned home from the hospital. In school settings it may be nurses whose ongoing support for children with disabilities ensures that their educational needs are met. Moreover, it may be a nurse midwife who helps new mothers with disabilities learn to care for their infants. We must consider the ways in which we can expand access to these rehabilitation services and broaden our scope of practice in this area.

Community Based Rehabilitation (CBR) is a relatively new model of care that has arisen in response to the failure of traditional models of care to provide comprehensive and empowering health care services. Generally, CBR is viewed by its organizers as opposing conventional expert-driven, and institutionally based medical models of health care that are disease focused. Instead, CBR promotes the idea that community resources must be developed in partnership with persons with disabilities, their families, professionals, and other local agencies to improve the quality of life for persons with disabilities by addressing problems at the local level. The spread of CBR has been credited to its being a culturally sensitive and grass-roots approach to disability services. As we re-think nursing care for persons with disabilities, we must consider the potential of CBR as an integral part of our new practice.

As we consider the significance and promise of nursing's involvement with CBR, we should also note that there are several potential problems that can occur with the use of this model. If people with disabilities are not included in decision-making throughout the processes of initiating and providing services, CBR programs run the risk of becoming hierarchical organizations that do not meet the needs of the populations served. As one disability advocate working in Cambodia put it before working with a CBR program "I always thought that CBR programs shown to foreign visitors as successful models were just shows. And they often really are!" (Zubiaga, 1997, p. 130). However, she then went on to describe how she decided to become involved in the restoration of a CBR program after observing the despair of 5 villagers following its sad ending. While it was not perfect, it had changed these 5 lives by linking them together for the first time. This advocate made the decision to work in the community to restore the CBR program, but only with the strong commitment of people with disabilities themselves. This example underscores the importance of asking the population served what they want before implementing CBR programs.

Nurses can play a role in helping to ensure that that the benefits of CBR outweigh its potential limitations. Specifically, nurses should use their knowledge of their local communities to identify and enlist the support of all key stakeholders, including people with disabilities and their families. As we strive to broaden our scope of practice in rehabilitation nursing, we must begin to identify and respond to the needs of people with disabilities, in ways that are not limited by traditional views. Again, we cannot stress enough the importance of learning from persons with disabilities themselves what their care should look like. This process will require that we begin to consider not only the importance of health-related issues in rehabilitation, but also the significance of other factors, such as education and employment as we devise strategies for change. Providing access to business opportunities, developing literacy programs, and helping women to obtain loans for cottage industries are just as vital to the health and well-being of persons with disabilities as many of the more traditional aspects of nursing care.

Support Services

We want to acknowledge the important influence of Vic Finkelstein's (1998) paper: Re-thinking Care in a Society Providing Equal Opportunities For All, as we endeavor to re-think nursing's role in support services for persons with disabilities. Finkelstein (1998) makes the critical point that "a culture of care evolved when support and care forms of assistance were separated (p. 8)," with the result that the care component tended to be isolated from families and communities and, over time, was transformed into professional services. This resulted in professionals, including nurses, assuming responsibility for providing care, with little, if any direction from persons with disabilities or their families. Consequently, support services were more likely to be designed, implemented, and directed by professionals without consulting the individuals or families for whom they were intended. Therefore, we see the role of nursing in re-thinking support services with persons with disabilities as especially important in the following three areas: 1) advocacy for consumer-directed support services and consumer evaluation of services; 2) attention to the support needs of families; and 3) facilitating the inclusion of consumer-directed support services in community programs.

Advocacy for Consumer Directed Support Services

Nursing needs to be a strong advocate for assisting persons with disabilities to participate in consumer-directed support services. Our definition of consumer-directed support services is "the ability of individuals to make the choices that allow them to exercise control over their own lives, to achieve the goals to which they aspire, and to acquire the skills and resources necessary to participate fully and meaningfully in society" (The Alliance for Self-Determination, 1996). This means that the choice to decide on the type, location, and amount of support services individuals want is self-directed. We recognize that this may present challenges to professionals, including nurses, who believe that they have the best knowledge about what, when and how support services should be provided. However, even though this belief may be well-intentioned, when others determine the nature of support services, individuals with disabilities are denied the opportunity to make their own choices.

Nursing is in a unique position to advocate for and assist with consumer-directed choice. This can be as simple as supporting a decision in a rehabilitation center to skip breakfast in order to prepare for a family visit. Or, it can mean advocating for a woman's choice to learn to perform self-catheterization rather than being forced to have an in-dwelling urinary catheter. Within a family it might mean that the nurse helps to arrange for a family member with a disability to learn to independently take a bus to a support group rather than always being accompanied. In the community, it may take the form of supporting an individual's choice to attend literacy classes rather than participate in work programs for the disabled.

The need for nursing to advocate for consumer-directed care is critically important in the design and execution of personal assistance programmes. The United Nations Standard Rules for support services (March, 14, 2000) includes a specific reference to the need for these programmes to be designed "in such a way that persons with disabilities using programmes have a decisive influence on the way in which the programmes are delivered (p. 3)" We fully agree with this and emphasize that the "decisive influence," should extend to all aspects of the programme, from its initial design, through actual implementation, to on-going consumer evaluation.

Addressing the Support Needs of Families

Nursing's traditional attention to the support needs of families hopefully just needs re-enforcing rather than re-thinking. In addition to carefully evaluating and helping to provide the support needs identified by individual families, nursing must assume responsibility for identifying and articulating their common needs and potential solutions. For example, if several families within a community identify a common need for temporary respite services, nurses should advocate for a community solution since this approach is likely to produce sustainable benefits for more families than narrower individual approaches.

Nursing also has a mandate to raise awareness regarding the need for providing family support services and the consequences of not providing that support. For example, in some developing countries where approximately 20% of the population have disabilities, the actual number of affected individuals can approach 50% when the adverse affects on family members is considered. This impact is often greatest among women and girls who are more likely than their male counterparts to assume care-giving roles. As a result, these female caregivers are also less likely to work or attend school.

Including Consumer-Directed Support Services in Community Programs

We have already addressed the need for nursing to work with communities in general, and with CBR programs in particular. However, we would like to emphasize here the need for nursing to actively incorporate their knowledge of what individuals with disabilities and their families identify as their support service needs at the community planning level. Using the example of identifying the need for respite services just described, this involvement should include not only bringing this need to the community's attention, but also working with families to design the type of respite service that would meet their needs. This may include arranging for transportation, determining the hours of operation and location, as well as the qualifications of the respite care providers. This is in no way meant to imply that individuals with disabilities and their families are not already playing key roles in designing the support services included in CBR programs. What we are saying is that nursing has an obligation to work collaboratively with individuals and families to keep the focus on the support services they need, rather on what others, including professionals think they need.

IDENTIFYING BARRIERS TO CHANGE

Throughout the process of re-thinking nursing care for persons with disabilities we have proposed many fundamental changes. These changes will not come easily because there are many real and deeply rooted obstacles in our way. We will briefly discuss barriers to changing nursing practice with persons with disabilities and offer suggestions to address these barriers.

The first barrier to change is resistance. Changing the ways nurses provide health care to persons with disabilities will require transferring power from nurses to persons with disabilities. Many nurses may be reluctant to give up their perceived power *over* in exchange for a sense of power *with* persons with disabilities. This kind of resistance undermines nursing's ability to expand nursing practice in the ways advocated in this paper. Stereotyping of persons with disabilities is another form of resistance to change. Nurses, like many other people, are uncomfortable facing disability because it increases awareness of our own human vulnerability. Rather than grapple with the meaning of disability in our own lives it often feels safer to view persons with disabilities stereotypically. These forms of resistance to change severely undermine our ability to provide individuals with disabilities the care they deserve.

The second barrier to change is the scarcity of human resources. A severe nursing shortage has been documented in many countries. We recognize that when nurses are in short supply, they are often required to spend more time supervising less qualified providers and/or focus primarily on providing basic physical care. In these instances there is little or no time to address psychosocial issues, move into expanded practice roles, or address the need for system-wide change. Until the availability of nurses increases worldwide, our efforts to expand nursing roles and access to health care for persons with disabilities will be a challenge.

The third, and most challenging barrier, is the social context within which nursing practice is embedded. This context includes discrimination based on gender and disability. Because nursing is a primarily female profession we have been influenced by gender discrimination. As a result, nursing has been relegated to less powerful roles in health care systems and society at large. Nursing's status in the hierarchy of health care poses a significant challenge to our ability to be heard and to define our own practice. In addition to gender discrimination, discrimination against persons with disability has also shaped nursing. Nursing has been unwilling to open the doors of the profession to persons with disabilities, thus limiting our ability to implement positive change. We cannot re-think nursing care for persons with disabilities and exclude them at the same time.

We believe education is *a key factor* in addressing these barriers. This should include awareness raising among nurses that focuses on assumptions and stereotypes regarding people with disabilities. It should also include developing and implementing basic and continuing education curricula in partnership with people with disabilities. This should result in highly relevant content, the experience of working with persons with disabilities as colleagues, and a view that supports self-directed care. Specifically, content should focus on preparing nurses to provide basic primary care, rehabilitation, and support services to people with disabilities, and developing the skills to become effective advocates.

The social context of nursing is a more difficult problem to address. There is no doubt that we must educate nurses to take leadership roles, to define our own practice, and to practice as we know they should. We also recognize, that while nurses may be changed through nursing education, the practice settings in which we work are slower to change. However, nurse Catherine Phiri of Malawi provides us with a powerful example of how one individual can make a significant difference in a community, despite multiple barriers.

CONCLUSION

Out task in this paper has been to re-think nursing care for persons with disabilities. We have relied on the United Nations Standard Rules (March, 14, 2000) and the disability and health literature to guide this process. As we envision what we would like nursing care of persons with disabilities to look like in the years ahead, the need for nursing to collaborate with the disability community to define that care has become evident. Our vision of that mutually defined care includes rethinking traditional practice roles, collaborating and participating in CBR, changing the nature of nursing education, and advocating for self-determination. We have urged that nursing's vision must include the need to address the widespread problems of violence and abuse, discrimination against women and girls, and inadequate access to health care, education, and employment for persons with disabilities. Attention to all of these contexts within each of the four preconditions – awareness-raising; medical care; rehabilitation; and support services – is essential to ensure that persons with disabilities enjoy full participation and equality in the societies in which they live. We sincerely hope that nursing will recognize its professional and moral obligation to help make that equality and participation a reality.

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