Understanding Disability From a South Indian Perspective

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ABSTRACT

This paper seeks to explore what it means to encounter “disability” within the context of South India, drawing upon both secondary published sources, as well as interviews conducted with disabled people and their families in receipt of CBR services from disability-specific NGOs working in the Indian State of Karnataka. The paper compares and contrasts the experiences of disabled people in relation to the medical and social models of disability. Specifically, the paper will consider community attitudes encountered by disabled people and their families in both rural and urban areas; the relation between poverty, employment and disability; the issue of marriage and sexual relations of disabled people; and the apparent gender bias in the provision of community-based disability services in the South Indian context.

The principal findings of this research showed that the notion of “disablement” is both socially and culturally defined. What is considered a “disability” within a western society may not necessarily be the case in a society such as South India. For example, a person in South India who has dyslexia will find it comparatively easy to obtain employment, where in a predominantly rural agrarian society, it is not a prerequisite to read to obtain work. This is clearly not the case in a country such as the United Kingdom, when a recent survey by the UK’s Department of Education and Employment found that three quarters of those with mental illness and two-thirds of those with learning difficulties are unemployed or in receipt of state benefits. This research also found that the principal needs and aspirations of disabled people were twofold - employment and marriage. Despite the fact the majority of disabled people were employed, there was great concern that all disabled people should be seen to make an economic contribution to the domestic household. This raises the self-esteem and dignity of disabled people, both in their own perceptions, and also amongst the local community. The research also found that disabled people valued the need for basic medical rehabilitation services, for this again directly assisted them in obtaining gainful employment. Finally, the research found there was a gender dimension to how disability is popularly perceived, and in terms of service provision. It was found that the level and severity of impairment had to be greater for women than for men, before it was socially acceptable for the latter to withdraw from economic activity within the domestic household. It was also found that men were more likely to receive and have more spent on rehabilitation services than are women.

The findings and inferences of this research have major implications for policy makers and practitioners providing community-based disability services. Historically, organisations providing CBR services have focussed on the provision of medical rehabilitation. Clearly there is a need for NGOs working in the field to broaden their remit, specifically to encompass activities such as disability awareness training and the provision of vocational rehabilitation. The provision of medical intervention should be perceived as a means to an end - not as an end in itself. Furthermore, practitioners should make concerted efforts to ensure that the services they provide are of equal benefit to both men and women.
1 Introduction

The purpose of this paper is to describe how “impairment and “disability” are encountered within a South Indian context, and what implications this has for the provision of disability services. It is impossible to provide a comprehensive analysis, since India is not only a country but a sub-content, with a population approaching one billion people. Therefore, the social, political and economic complexion of India is extremely diverse, particularly in terms of its class and caste composition and the diversity of religious faiths found within that country. This paper is based upon research, the majority of the material collected for this paper was collected during fieldwork for a PhD registered within the School of Development Studies, University of East Anglia, in the UK, but also draws upon the limited secondary sources that are available. The thesis described and critiqued the theoretical understandings of disability, and the philosophy and operational practice of Community-Based Rehabilitation (CBR), before considering how each of these can mutually enhance and develop the other. This paper will focus upon the experience of disablement within a South Indian context. Due to time constraints, discussions surrounding the efficacy of CBR as an appropriate strategy for the provision of disability services are omitted from this paper. Similarly, discussions concerned with the demographics of impairment, which are controversial and complex, are also omitted.

The primary data was collected from four disability-specific NGOs providing community-based rehabilitation services in the vicinity of Bangalore, South India. These were the Shree Ramana Maharshi Academy for the Blind (which administers the Sourabha CBR programme); the Association of People with Disabilities which administered an urban-based CBR programme in the slum areas of Bangalore; Abilities which manages a large CBR programme, entitled Vikasa. This is a rural-based CBR programme located approximately 60 km north-
east of Bangalore. All of the above projects were funded by ActionAid (India). Finally, Seva-in-Action provides CBR services in 147 villages throughout Karnataka.

2. How Disability is Perceived and Experienced in South India

2.1 Data Sources

The objective of this section is to explore what it is like to experience and what are the implications of having an impairment in a social context such as found in South India. As an integral part of the fieldwork conducted for this research, disabled people and their parents were specifically asked about the manner in which they perceived their own disabilities and the social attitudes they encountered within their local communities in relation to their impairments and disabilities. They were also asked questions about what problems and difficulties they encountered as a result of their impairments, as well as what their needs and aspirations were for the future. The vast majority of those interviewed were clients in receipt of services provided by the four disability NGOs that agreed to participate in this study. It therefore could be said that the disabled people interviewed were untypical of the majority of disabled people who live in Karnataka, since the majority are not in receipt of any services whatsoever. Where respondents had a severe cognitive impairment, their parents spoke on their behalf.

The analysis presented below does not claim to be representative of the manner in which disabled people are generally perceived throughout India as a whole, nor indeed solely within the State of Karnataka. The data presented only provides a snapshot of the attitudes encountered by those who took part in this study. However, the conclusions and inferences that are drawn from the fieldwork concur with the analysis of other small scale anthropological studies that have previously been undertaken regarding disability in South India.
In total, approximately 70 disabled people participated in interviews conducted for this research, two-thirds of whom were men. Furthermore, the number of disabled people who participated in a single interview varied significantly. Due to the nature and logistics of the fieldwork, some interviews, (for instance, those conducted at Abilities) had as many as twenty people, while in other instances, individuals were interviewed on their own. However, it was invariably the case that the quality of interviews was greater in group settings than when disabled people were interviewed individually. The range of impairments encountered by the disabled people who participated in this research were very diverse. They included those who were totally blind, those with partial or extremely limited vision, polio, cerebral palsy, as well as amputees who has lost one or more of their limbs as a result of an industrial or agricultural accident.

In contrast to the Erb and Harriss-White study described below, it was invariably the case that it was not possible to collect reliable data regarding the caste and class social composition of those interviewed. Nor was it possible to collect accurate statistics regarding their age composition. To date, there has been a dearth of similar studies undertaken in the Indian subcontinent. Analogous anthropological studies have been conducted in other developing countries - notably in Central Borneo, Kenya, Southern Somalia, Uganda, Nicaragua and Botswana (Ingstad, B. and Reynolds White, S. ed 1995), and these offer useful insights, although it should be remembered that this research was not structured as an anthropological study. Susan Erb and Barbara Harriss-White conducted an anthropological study of disability in three rural villages in Tamil Nadu, the adjacent state to Karnataka. The fieldwork for their study took place in 1995 over a four month period, but has still to be published. However, the authors have generously made available to me a draft copy of their research findings (Erb, S. and Harriss-White, B. 1996). It was considered important to incorporate the research findings and inferences of this particular anthropological study with the primary data collected for this research, in the belief that such a process would result in a more nuanced and enriched
understanding of what it is to encounter disablement in as society such as found in South India.

The objectives of the Erb and Harriss-White anthropological study were three-fold:

4) to examine what disabled people actually do and how they interact within a rural agrarian society as found in Tamil Nadu;

5) to examine the costs associated with adult disability within the context of a local economy that is largely dependant upon manual hard labour;

6) to examine to what extent disabled people had access to disability services provided by both the public and voluntary sector.

The fieldwork for the Erb and Harriss-White study was undertaken in three villages in the Walajabad Block of Chingleput District in Tamil Nadu State - Thammanur, Vitchanthangal and Kalur. Each of the villages contained 250-300 households, with 1,400 individuals. All three villages consisted of a main settlement as well as an adjacent harijan colony, the latter solely for those from scheduled castes. This combination was considered essential by the researchers, so as to ensure that the entire spectrum of caste composition was included within the study.

It was considered that disability should be self-defined by individuals and their family members. By so doing, it was

.. hoped to establish an understanding of how disability is experienced within the village and of the historical events, and medical, economic, social and/or religious factors responsible for creating handicaps from disability. (Erb, S. and Harriss-White, B. 1996:30).

The Erb and Harriss-White study showed in the main settlement of Thammanur 35 men and 84 women (or 12
per cent of the total adult population) had a self-defined impairment. Within the Vitchanthangal and Kalur Main Settlements, there were 48 adults with impairment, constituting 10 per cent of the adult population. In the main settlements of these villages, loss of vision or blindness was cited as the principal cause of disability. The other major causes of impairment were associated with aural and orthopaedic difficulties. The portfolio of disabilities found in all three colonies were found to be different from that found in the main settlement. Those living in the colonies had a greater severity of impairments, with few mild and moderate disabilities.

2.2 Community Attitudes Towards Disabled People

The inferences and findings reported in this section draws exclusively upon the interviews conducted specifically for the PhD. The disabled people who were interviewed encountered a multiplicity of reactions and attitudes from members of the local communities. It was stated during the course of several interviews that many community members showed a complete lack of understanding and awareness of the problems and issues encountered by disabled people. For example, the disabled men interviewed at Sourabha=s TRDC training programme considered that they had become objects of pity, derision and should be shut away and cared for by their parents. Similarly, a group of disabled people attending Abilities Saturday programme, who were primarily blind, stated that was invariably the case that the general public did not recognize that they were blind, and when they did so, were unsure of how to help them. However these disabled people were generally invited to social functions, but invariably felt uncomfortable in attending. Mahesh, who participated in the Saturday Programme ran by Abilities, provided an example where he felt such embarrassment.

_Recently I went to a wedding. This place was fully carpeted. There was a buffet dinner. After dinner I didn't know where to keep the plate, so, I asked one of my relatives to help. He took the plate and went away. As I was standing there many people came to talk to me and some were trying to shake my hand. I had a paper napkin in my hand, I looked here and there but I couldn't find a place to throw it. so, I put it in my pocket and took out my handkerchief and wiped my hand. This is one of the reasons why most of us don't like to go to functions, and if we do go, we generally sit in a corner because_
Furthermore, disability is commonly associated with religion, sometimes attributing to disabled people almost god-like powers. It was commonly believed that disabled people possess extraordinary powers and gifts, and therefore do not actually perform common, everyday activities, such as having to eat and sleep. The attitudes reported by some of the disabled people interviewed were indeed very positive, which contrasts strongly with the popular perception in India that the root cause of disability is attributed to sin and destiny - karma. This may be accounted for by the fact that many of those interviewed live in urban areas, where western conceptions of the etiology of disability and impairment are more common place. Furthermore, those interviewed lived in rural areas where NGOs were already providing some disability services, and it is likely that local communities will have received and benefited from some form of disability awareness education or campaign.

Beliefs regarding the causes of disability varied between urban and rural areas. Within the former, beliefs regarding the etiology of impairments are more likely to equate with western understandings, that take account of explanations derived from medical science. However, within rural areas, the causes of disability and resulting impairments are frequently seen in a religious context. Within the traditional Hindu religion, disability is sometimes perceived to be the result of karma, whereby impairments and the resultant disability is considered to be the result of either the sins committed by one's parents, or alternatively, the consequence of the sins that one has committed during a previous life. Hence, disability is perceived as a recompense or retribution for past misdemeanours. The understanding given to the presence or absence of impairments certainly has a moral dimension to it. Mr. Pankenel, (an independent disability consultant based in Bangalore), was of the opinion that there was widespread ignorance regarding the causes of disability throughout India. The Hindu notion of karma hindered the effective development and implementation of CBR). One participant who was interviewed at the
Sourabha’s CBR training centre stated the following:

> Whether people in the community have met disabled people or not, they still believe that disability is a result of karma or sins of the past. Disabled people and their families are despised. People are afraid to come in contact with disabled people. They think that disability is contagious. Some people in the community tell people to avoid disabled people because they might also attract the bad luck of the disabled person and the family. (Group Interview with Disabled People, TRDC, Sourabha CBR Programme - 3rd April, 1997).

The interview conducted with disabled people who were clients of the Vikasa CBR programme provided evidence that, in remote rural areas, the causes of disability are sometimes attributed to the practice of black magic. An instance was cited that on one particular occasion, a person who owed a large amount of money to another, but failed to repay his debt within the designated time, had a curse placed upon him. Subsequently, the man became blind. More generally, it was popularly believed that occult practices were widespread within the local community, even to such an extent that local politicians used the threat of black magic in order to secure votes.

Father Cultinha, from the Divine Light Trust for the Blind, maintained that the degree to which disabled children were accepted by their families, and the extent to which these families accepted their child’s disability was contingent upon the family’s social status. Disabled children that are born into both low and high status families often encounter difficulties in being accepted within their own families, but for different reasons. Upon commenting on this state of affairs, Father Cultinha stated:

> The acceptance level of disability in the family even now varies to a great extent. A total acceptance is hard to find even today. I would say, from my experience. I am not belittling the families, but total acceptance, is very difficult to find. Take from the lowest strata, the poor, the marginalized, poverty line as you say. For them it is a question of existence. (Interview with Father Cultinha, Divine Light Trust for the Blind - 24th October, 1997)

The ability of disabled people to participate within society, particularly when they are children is exacerbated by the fact that many mothers feel very conspicuous when taking their children into public places. Members of the
local community would often stare at the disabled child, causing the parents to feel miserable. Furthermore, it was stated that some parents with non-disabled children actually forbid their children from playing and interacting with those with disabilities, fearing that the impairment may be contagious and may also be related to anger from the gods.

Children with disabilities are likely to experience further isolation and exclusion from their local communities, because some parents feel a great deal of shame, remorse and guilt because of their child’s physical or cognitive condition. In such situations, there is a tendency for parents to attempt to shun away their children. I have been told of instances where children have literally been locked up in their houses, in an attempt to hide them, thus avoiding their public disgrace. During the course of interviewing Mrs Chatterjee, Principal Secretary at the Ministry of Welfare, New Delhi, I was told of an instance where one very high ranking civil servant had an 18 year old son with cerebral palsy. The father, because of his high social position was fearful of the public disgrace that would be inflicted on his family because of his disabled son, and had actually incarcerated his son in a bamboo cage for the first 15 years of his life. This action indicates that social standing within society is all important within India, even to the extent of being detrimental to members of one’s immediate family. However, there is evidence to suggest that this instance of abuse is not an isolated case, but is commonly encountered by disabled people, particularly in the case of women (International Disability Foundation, 1999:82).

The case described in the previous paragraph is somewhat different from the experiences of the disabled people interviewed for this research. This may be explained by the fact that the majority of the disabled people interviewed probably did not come from very high caste or high class social backgrounds, and social prestige and status were not so important for them. However, during fieldwork, data regarding the caste and class structure of respondents was not collected, so this proposition remains speculative. It would indeed be interesting to
investigate in subsequent research, if there was indeed a positive relationship between social status and the extent to which disabled people are excluded from participating in community life. Again, the fact that disability-specific NGOs have been working in the catchment area where respondents live, thereby raising the general level of awareness concerning disability issues, may also be a contributory factor in explaining more positive attitudes.

There is also evidence from the fieldwork data that disabled people encounter and experience social exclusion and discrimination. For example, some blind respondents from Abilities were told that the bus was full when in reality, it was only half full. Disabled people who were trainees at the TRDC Training Centre attached to the Sourabha CBR Programme stated that, in general, the local communities from which they came were unsympathetic to their condition. Also, it was a commonly held perception that it was a waste of resources to educate a blind person to degree level, since they will not be able to fully participate in society. They were treated as objects of pity and were subjected to outright derision. Furthermore, some community members considered that it was an inappropriate use and waste of resources to provide vocational rehabilitation to those who were disabled, believing that it was unlikely that such initiatives would result in employment. One respondent interviewed are Sourabha=s TRDC Training Centre poignantly stated:-

Many people look at us with pity. Some despise disabled people. But there are instances when people help a disabled person. E.g. to get into a bus. However, by and large the attitude is very negative. People in the community very often, move away quickly when they see a disabled person because they feel he is a beggar. People in the community will try to avoid contact with a disabled person. But we have to accept both the positive and the negative sides and get on in life. Once we are trained and become economically independent, self-reliant people, people will respect us a little. We will have some status in society. (Group Interview with Disabled People, TRDC, Sourabha CBR Programme -3rd April, 1997)

Disabled people not only encountered hostility and negative social attitudes from members of their local communities, but were also subject to exploitation by local government officials. The group of trainees interviewed at TRDC, the majority of whom had polio, stated quite explicitly that they had to pay bribes to local
government officials in order to receive medical certificates that certified that they were in fact disabled. These certificates were necessary in order to receive a state allowance of Rs 100 per month to which disabled people are entitled. They also had to pay bribes in order to continue to receive their monthly allowance. Thus, over say a three month period, they would invariably only receive Rs 100. Commenting upon the issue of corruption they stated:-

_Government officials are callous, they take bribes, they are corrupt, and have no interest whatever in disability. Disability services can never be provided by officials at the taluk level or by any government office. Even in the case of job reservations for disabled people, there is corruption. Government officials tell disabled people very frankly that they will not get enough money as bribe from disabled people, so they are not interested in giving disabled people jobs._ (Group Interview with Disabled People, TRDC, Sourabha CBR Programme -3rd April, 1997)

Due to the endemic corruption that characterises local government, these respondents were of the very strong opinion that it would be disastrous if community-based disability services were financed and managed by local government at the Taluk level. It was believed that financial resources would be siphoned off by government officials for other uses.

2.3 The Relationship Between Poverty, Employment and Disablement in India

The analysis and findings of this section is primarily derived from the Erb and Harriss-White anthropological study, but it also supplemented be some material derived from the fieldwork interviews. It is readily apparent from the analysis of the primary and secondary sources of data that there is a direct and symbiotic relationship between poverty and disablement. Thus, it can be stated that poverty is both a cause and a consequence of disability. The importance of this relationship is increasingly being recognised by the international donor community, and has been given prominence in the recently published position paper on Disability and Development by the UK Government’s Department for International Development (Department for International Development, 2000). In commenting upon this complex relationship in the Indian context, Erb and Harriss-White stated:-
Disability and poverty are closely related. While disability causes poverty, in a country with mass poverty it is also possible that poverty causes disability. The mechanisms are malnutrition, exposure to disabling disease, inadequate access to inadequate preventative a curative health care and an enhanced risk of occupation-related accident among the poor. The relationships between poverty or deprivation (economic disability), weakness or vulnerability (social disability) and medicalised disability results in simultaneous deprivation. (Erb, S. and Harriss-White, B. 1996:5 -6).

The Erb and Harriss-White study found that there was indeed a direct relationship between poverty and disability. The study examined the additional economic costs associated with the onset of disability. Three categories were identified - the direct costs of medical treatment and rehabilitation; the indirect costs (for example, costs of transportation); and the opportunity costs, constituting the income forgone, due to being incapacitated or restricted in economic activity. For all three villages, the vast majority of medical care provided was locally accessible, but costs varied enormously, ranging from Rs 75-150 for a clinic visit to Rs 10,000 for open heart surgery. The most common form of treatment were visits to the local clinics for pain relief, information-gathering consultations, leprosy or TB treatment, costing on average Rs. 1,200 (1995).

The Erb and Harriss-White study also investigated the needs and aspirations of disabled people, examining the gap between the services that were currently being provided and those requested and needed by disabled people. It was found that the primary needs, as expressed by disabled people and their carers, were for basic restorative equipment - spectacles, orthopaedic aids and hearing aids. However, for most people with visual difficulties, their impairment was too mild to qualify for government assistance, but in many instances, the lack of spectacles precluded them from participating in economic activity.

The opportunity costs associated with disability were readily apparent. Within the research area, it was found
that 34 men and 18 women had completely lost their occupation as a direct consequence of the onset of their
disability, and a further man and eight women had lost unwaged labour. Erb and Harriss-White identified the
detrimental effect - in half of the cases of male disability and in over one-third of female disability downward
economic mobility results from the loss of labour by the disabled individual (Erb, S. and Harriss-White, B.

The impact of poverty, (as defined as loss of and inadequate income) and disability was also reflected in the
fieldwork data collected for this research. Father Cultinha, from the Divine Light Trust for the Blind was of the
opinion that disabled people from low status families are often perceived as an economic burden. Endemic
poverty often characterises low status families, which was further exasperated by the presence of a disabled child
who is unable to provide an economic contribution to the household. Disabled children from high status families
sometimes find being accepted by their families difficult, due to the fear of bringing social disgrace and
embarrassment upon them. Also, the prevalence of having a disabled sibling within the family is likely to be greater
within low status households. Once again, this highlights the positive relationship between disability and poverty
already discussed, since those living on very low incomes are susceptible to malnutrition, a lack of sanitation, poor
housing and so forth.

Given that households with a disabled family member were often living in circumstances characterised by
endemic poverty, it is not at all surprising that the principal aspiration of disabled people was to gain employment,
thereby being able to make a financial contribution to the domestic household. This was reflected in both the Erb
and Harriss-White anthropological study and through fieldwork interviews. Indeed, the Erb and Harriss-White
study, which employed a self-defined working definition of disability, found that the ability of a person to be
engaged in gainful employment determined whether an individual was deemed to be disabled. Erb and Harriss-
White stated:

... disability is determined according to whether or not an individual is able to work. Conditions such as pain, alcoholism and >swelling =, to name a few, are conditions which are not disabling in a western setting, but are disabling in an agricultural and rural economy dependent upon sustained manual labour (Erb, S. and Harriss-White, B. 1996:82).

The above quotation, where disability is defined in terms of whether a person has the ability to work, raises serious questions about the western-constructed distinction between disability and ill health, and is of relevance to the previous discussion regarding the applicability of the medical and social perspectives of disability discussed previously. If this understanding was applied elsewhere, medically constructed definitions of disability would be inappropriate and misplaced. In addition, the proposition that medical interventions and treatments result in the cure or amelioration of impairment, which in turn improves the quality of life enjoyed by disabled people, has to be queried. It appears that the appropriateness and validity of medical intervention and rehabilitation is far more nuanced than the medical perspective, in its purest form, would suggest. The notion that pain, swelling and the onset of old age constitute impairments surely questions the notion that disability has nothing to do with the body. It is possible to perceive, from such a self-defined conceptualisation of disability, that impairment is socially constructed, and that recent calls for the development of a sociology of impairment are indeed pertinent and timely.

The disabled people who participated in interviews for this research stated that they faced a multiplicity of problems, but two stand out for particular attention, these being employment and marriage. The interviews showed that the dignity and self-esteem of disabled people, both within their own estimation and as perceived by others, was contingent upon financial security and the ability to obtain employment. This must be perceived within a context where disability is often equated with begging and pauperism. For example, both of the disabled women interviewed at the Sourabha vocational training programme explicitly stated that their dignity, self-worth
and self esteem was contingent upon them obtaining employment. The relationship between the importance of gaining employment and the consequent rise in the dignity and self-esteem of disabled people, (both in their own estimation and within their local communities), was also confirmed by the findings of the Erb and Harriss-White study. They found that the most critical factor in determining whether disabled people are accepted within their local communities was contingent upon whether they were employed, either by undertaking waged labour or by contributing to domestic work. They stated:

*In an agrarian economy, it is only in very severe cases of physical disability and/or extreme old age that disabled village adults do not work. It is both the expectation of the disabled individual and of their household members that they engage in work in order to contribute to the household income. If they are unable to work for a wage, either for reasons of caste or gender, or because of physical inability, the individual will be expected to contribute to the household through housework, child care and/or animal care. (Erb, S. and Harriss-White, B. 1996:54-55).*

Within Thammanur village, approximated two-thirds of disabled people worked in some way, with roughly half receiving a waged income. In Kalur and Vitchantangal, it was found that approximately 60 per cent of disabled people were engaged in economic activity. Despite the fact that the majority of disabled adults were thus engaged, in an agrarian and largely subsistence society the onset of impairments resulted in an economic shock to the household concerned, and are indisputably pauperising (Erb, S. and Harriss-White, B. 1996:55).

It is interesting at this juncture to draw a comparison with employment rates for disabled people within Great Britain. The Department for Education and Employment, as part as its last Labour Force Survey, published in Autumn 1999, examined the relationship between disability and employment (Department for Education and Employment, 1999). The Survey found that although disabled people constitute nearly a fifth of the working-age population in Great Britain, they nevertheless constitute one-eighth of all those in employment. Furthermore, disabled people are over six times as likely an the able-bodied counterparts to be unemployed and claiming state
benefits. When disabled people are employed, they are more likely to be self-employed and work part-time. The Survey also found the employment rates vary according to type of impairment. Some impairment groups, such as those with diabetes, skin conditions and hearing impairments attain relatively high employment rates. However, three quarters of those with mental illness and two-thirds of those with learning difficulties are unemployed (Department for Education and Employment, 2000). It can therefore be appreciated that the prospects of disabled people gaining employment are far greater in South India than they are in a western country such as Great Britain.

Thus it can be seen that the provision of basic medical and rehabilitation services is of primary importance. This has implications for the main thrust of the argument being developed in this paper. Those disabled people who participated in the Erb and Harris-White's study clearly wished to receive basic rehabilitation services, with the expectation that such services would alleviate the detrimental consequences of living with an impairment. Mitigating the effects of impairment increased the probability of disabled people being able to work, which in turn facilitated the raising of their self-esteem and acceptance within the local community. Hence the provision of basic rehabilitation services was perceived as a means to an end, with the ultimate objective being to secure gainful employment.

The findings presented above are of interest and importance to policy makers and practitioners working in the field of disability and rehabilitation. Firstly, NGOs providing CBR services have historically perceived the provision of medical rehabilitation services as the ultimate goal, without taking a more holistic perspective to disabled people's needs and aspirations. However, this is now beginning to change. Secondly, the analysis of the primary and secondary sources of data presented above show that despite the fact that the majority of disabled people are engaged in employment, it is nevertheless the case that securing and maintaining employment, thereby making a financial contribution to the domestic household, remains of utmost importance. A plausible explanation
for this may be the social stigma that is attached to not being able to make such a contribution. It seems to be the case that disabled people are considered outcasts and socially excluded from the mainstream of society if they are unable to make a contribution to the domestic household. Notwithstanding the relatively high proportion of disabled people who are engaged in economic activity, disabled people and their families wish to avoid unemployment at all costs.

2.4 Marriage

In addition to the precedence given to the ability to secure employment, the disabled people who were interviewed for this research also identified marriage and sexual relationships as an important need and aspiration. The importance of marriage was perceived differently by disabled men and women, and was structured according to stereo-typical views of their respective roles within the family. Disabled women expressed the opinion that they were in fact apprehensive of getting married, fearing that they would be unable to cope with the pressures and responsibilities of marriage particularly regarding childbirth. Commenting upon the prospects of marriage, one of the disabled women at the TRDC Training Centre stated:

*Our major problem is that society doesn’t accept us because of our disability. We will not be able to get married or get a job. But because we are trained we can have some earning of our own and look after ourselves. We also don’t want to get married and be abandoned by the husband as is the experience of one the women here. I would rather wait until I meet someone who understands my disability and is still prepared to marry me and look after me.* (Group Interview with Disabled People, TRDC, Sourabha CBR Programme - 3rd April, 1997)

For many disabled women within India, the prospect of marriage is beyond the realms of possibility. Also, one of the respondents, who was blind, stated that she had married, but she had been deserted by her husband, who had left her for another woman. This had, quite understandably, made her reticent to enter into another relationship. The families of disabled women also face the additional hurdle of securing and paying a sufficiently large dowry to pay to the potential bridegroom’s parents, as a bride who is disabled may be considered second rate so
requiring a larger dowry. Within Hindu society, young women with impairments might marry, out of necessity, someone from a lower caste then themselves. Commenting on the prospect of marriage for women who are blind, Esther Boylan stated:-

Attitudes and ignorance are particularly virulent where blind women are concerned - no one would readily consider marrying off a blind girl or asking for her hand in marriage. Objects of false pity and mindless charity, blind women are often regulated to the lowest status within the community - they are isolated from society and confined to a corner of the house and live in obscurity, silent misery, and total social and economic obscurity (Boylan, E. 1991:3-4).

Disabled men interviewed for this research, however, considered the prospect of marriage in a totally different manner. While acknowledging that the prospect of getting married was going to be more problematical than for their able-bodied peers, the majority of them nevertheless were mildly confident of doing so. Some of those interviewed who were blind expressed the opinion that they would prefer to marry someone who was able-bodied, for they would be able to assist in overcoming the difficulties and problems that are encountered as a result of impairment; and be in a better position to undertake the functions associated with child-rearing.

It is duly recognised that there are other significant issues that disabled women, within the context of marriage, that have not been addressed by this thesis. These include the right for disabled women to enjoy sexual pleasure, the implications of having an impairment in relation to the social legitimacy of reproduction, as well as social security issues within the context of marriage. Due to the highly sensitive and controversial nature of these issues, little, if any material has been published in this area. However, they have been discussed at a number of fora, for example a seminar that took place on the inter-relationship be disability and development issue as the 1999 annual conference of the Development Studies Association at the University of Bath. It is timely that these issues are documented, and would indeed constitute an important area of study in future research.

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2.5 The Gender Dimension to Disability

A further important factor to that is potentially of major importance when discussing the provision of disability services in a society such as India is the social position of women with disabilities (Morris J. 1991; Lonsdale, S. 1990; Boylan, E. ed. 1991). From the analysis of both primary and secondary sources, it is readily apparent that disabled women, both in India and internationally, have a relatively lower status than do their male counterparts, and are thereby are less likely to receive and benefit from the provision of rehabilitation services. From the discussion of the estimates of those with cognitive impairments in the previous section, It is interesting to note that small scale studies have showed a men:women gender imbalance in the prevalence rate of mental disabilities in the order of 2:1 (Subramanya, B. 1983). Thus, as in the case with physical and sensory disabilities, it does indeed seem the case that men are more likely to be impaired than are women. Again, it is difficult to be certain why this should be the case, and any explanations given can only be considered as speculative. The issue of the inter-relationship between gender and disability is increasingly becoming a topic of interest and discussion within the field of disability studies.

As will be shown in greater detail, the plight and quality of life of disabled women in India is substantially worse than it is for men. Within the Indian context, there is anecdotal evidence to suggest that disabled women have been deliberately neglected and even been left to die, as well as encountering sexual harassment and assault. The World Disability Report stated that women with disabilities are at a very high risk of receiving such treatment, with some studies suggesting that they have twice the risk of being sexually abused as their able-bodied counterparts (International Disability Foundation, 1999:88). The HELP Library on Health Information, Bombay, in the information contained on their web site,
commenting upon improving female mortality rates stated:-

These are the results of sex-related abortions or instant post-natal deaths due to deliberate neglect or killing of newly-born female children through purposeful withdrawal of nutritional or medical interventions or even physical murders, undetected or overlooked by the law enforcing agencies. The inevitable consequences of these (mal)practices is the adverse sex-ratio for females and its adverse decline from 972 per 1,000 males in 1901 to 927 females per 1,000 males in 1991. ... [Consequently] A sizeable number of girls and women with disabilities are permanently in poor health. In addition to a number of specific diseases they remain weak and at great risk of falling ill frequently. They are not provided with rehabilitative services and are confined to their homes. (HELP Library.2000.)

Hence, within the Indian social context, women are regarded as inferior beings, both by able-bodied and even disabled men. Being deprived of basic health services at birth and during early infancy, educational opportunities during their childhood, and often genuine love and affection, it is far from surprising that disabled women=s lives in India are characterised by a lack of self dignity and worth. Anecdotal evidence provided from the interview conducted with a group of parents at the Anekal CBR programmes suggest that fathers invariably ignore the fact that they have a disabled child, particularly if the child is a girl. One mother stated during the interview, when the child is unwell, the family tells me not to bother with getting medical help or taking her to the doctor so that the child could die. Commenting upon the plight of women throughout the developing world, Boylan stated:-

In developing countries, a woman=s status is considered to be subjugated and dependent. Families in rural areas do not send their able-bodied girls to school once they attain puberty. Even within the sisterhood of women with disabilities, there are those whose handicaps provoke even further discrimination, particularly the mentally retarded and the blind. (Boylan, E. 1991:3).

The disadvantaged position of disabled women in comparison to disabled men is confirmed by other national and cross-national studies. In both industrialised and developing counties, evidence suggests that the plight and social status of disabled women, measured by a multiplicity of indices, is indeed lower than it is for their male counterparts. In general terms, within industrialised societies, disabled women are
likely to earn less income, have a lower level of education and are less likely to be employed than men (Bowe, F. 1984). Ann Elwan, in an unpublished paper, examined the relationship between poverty and disability. She cogently reviews the plight of disabled women throughout the developing world. She stated:-

Several articles contain case studies and other types of reports on the poor social status afforded to disabled women. A study by ESCAP [ESCAP, 1995] notes that the difficulties faced by disabled girls starts from birth, and that if disabled girls are allowed to survive, they can face discrimination within the family, receive less care and food, and be left out of family interactions and activities. They also have less access to health care and rehabilitation services, and fewer education and employment opportunities. Disabled women are at a high risk of being abused physically and mentally, sometimes from within the household. ... ESCAP notes that the access problems confronting women with disabilities are more severe in rural areas; higher literacy rates, and longer distances compound the difficulties of inadequate access to information, health care and rehabilitation services. The Blind Men=s Association of India attribution of higher rates of blindness among women to the lower likelihood of females to be transported to the city to have the necessary medical care for eye diseases. (Elwan, A. 1999:21-22).

A further set of issues that have a significant impact upon how disability experienced in India centres around central issue of gender inequalities. This issue has a number of strands that will be explored below. Firstly, there is a calculus of different social expectations and responsibilities that are ascribed to disabled people, differentiated by their gender. Secondly, the secondary data suggests that disabled men a more likely to receive and have more spent on rehabilitation services than are disabled women. Thirdly, within the context of the domestic household, it is predominantly the women who provide the vast majority of the care for disabled family members.

Erb and Harriss-White found evidence that the severity of disability had to be greater for women than for men before the former were absolved from the responsibility of being economically active. There is an implicit social expectation that women who become disabled will continue to perform domestic duties within their home. Erb and Harriss White stated:-
Gender ideology affects work burdens for disabled adults emerging in a severe social disadvantage for disabled women who were found to be treated more unfavourably than men. Because disabled women more easily maintain their household contribution through domestic labour, their disabilities were less conspicuous than those of their male counterparts. (Erb, S. and Harriss-White, B 1996:155).

There was also a gender bias in relation to access to medical treatment, with women being at a disadvantage in comparison to men. Within the main settlements, between one-third and one-half more men received medical treatment. Furthermore, households spent considerably less on clinical care for women—on average 74 per cent less. For disabled women living in the colonies, medical treatment was not a household priority at all (Erb, S. and Harris-White, B. 1996:105). It was readily apparent that disabled women in South India face a harder and more precarious lifestyle, than their male counterparts. In summarising the poor status of disabled women in India, Erb and Harris-White have stated:-

While slightly more women than men acknowledge themselves as disabled, domestic work hides both the condition and its impact. Women’s domestic work is a compulsory prior which is difficult to negotiate. We might infer from social relations behind these village statistics that considerable more women may be disabled than are men, but that fewer may be able to declare themselves incapacitated. Women also recognise themselves to be disabled at a more advanced stage than do men. Even when forced to withdraw from agricultural labour, half of the disabled women continue to perform domestic work. (Erb, S and Harriss-White, B. 1999:1)

This research also indicates that there is a further dimension to the gendered nature of disablement within the South Indian context, with the majority of care for a disabled family member being provided by women. The interview conducted with groups of parents from the Anekal CBR Programme run by Seva-in-Action provided strong evidence that it is the mother, and sometimes the grandmother who provide the vast majority of the care. The pivotal role of grandmothers in the rearing of disabled children is prevalent in other cultures, for example, among the pastoral Masai tribes in Kenya (Talle, A. 1995:65). Indeed, in some instances, the father wanted nothing to do whatsoever with their child, ignoring any recognition of his or her presence and needs. Prevalence
of such attitudes had an extremely detrimental impact upon the physical and emotional health of these mothers. Many expressed feeling hopeless and helpless, exhibiting a demeanour of total resignation to their own fate. As a result, many of these mothers felt trapped in the time consuming role of caring for their disabled children, and also felt ignored and neglected. One mother, in her late 20s, had a daughter with cerebral palsy and severe learning difficulties. At the time of interview, the daughter was aged twelve. The mother stated that the burden of caring for her daughter, with no support from her husband, had got so overwhelming that every day she told her daughter that she wished she was dead. One can only speculate what the enormity of the negative psychological impact this had upon the child. Commenting upon the implications of bring up and caring for a disability child, the parents attached to the Anekal CBR Programme, administered by Seva-in-Action stated:-

We feel a great sorrow, a sense of deep sadness because there is a disabled child at home. We don’t participate in community functions. We don’t visit the homes of any of our neighbours or friends, because the disabled child needs constant care and because we are not welcome. We have to care for the disabled child all our lives and we feel it is a very heavy burden, a strain and a great responsibility for the rest of our lives. We cannot have any personal interests, we cannot do any other work apart from caring for the disabled child, because we cannot leave the disabled child alone. So we feel tied down to the disabled child. (Group Interview with Parents of Disabled Children, Anekal CBR Programme Seva-in-Action - 19th March, 1997)

The Erb and Harriss-White study also found that the vast majority of care was provided by women in the domestic household, where it was just assumed that they would incorporate the additional burden associated with caring into their other domestic responsibilities. The study found that for all intents and purposes, caring for a disabled family member precluded female members of the household from being able to be engaged in paid employment. The average income lost to the household as a result of caring for a disabled family member was equivalent an average monthly agricultural wage. This scenario inevitably places additional economic strain upon the domestic household, thus reinforcing the comment regarding the relationship between poverty and disability made previously.
It was also found that the level of acceptance of disabled people within their own family varied. Some are fully accepted and loved, while on the other hand, some parents want to just get rid of the disabled child. These sentiments were stated by parents associated with the Anekal CBR programme. Some disabled children are neglected in preference to other siblings. Again there is a gender bias when consideration is given to provision of care for the disabled child within the context of the family. The extent to which some parents will go, in the face of inadequate resources, is only to be commended. Given this lack of resources, there is a very real danger to the very lives and well-being of disabled children, particularly if they are females. Again, this confirms the earlier discussion and analysis regarding the difference in sex ratios in infant mortality rates vis-à-vis disabled people.

3 Conclusion - Applying the Medical and Social Perspectives of Disability in South India

The objective of this concluding section is to critically assess the how applicable are the social and medical perspectives of disability when they are applied within a South Indian context. It is assumed that the readership of this paper are conversant with the central tenets and respective critiques of the social and medical which are summarized in Box 1 below.

<table>
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<th>Box 1 Comparison of the Medical and Social Model of Disablement</th>
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<td><strong>Core Features</strong></td>
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Insights

- Objective of social policy is to enable Disabled people to “fit into” or adapt to the structures of contemporary society;
- The vast majority of disabled people wish to receive high-quality Rehabilitation;
- Services. What is at issue is the nature of the relationship between able-bodied Professionals and “clients”;
- Perspective emphasises professional Expertise; disabled people need to adjust, be controlled and be cared for, to be accommodated into the needs demanded by the so called “able-bodied world”.

- Objective of social policy is to create an environment that “empowers” disabled people to secure their human rights;
- Disabled people encounter systematic social exclusion within society;
- Social change comes through collective action to secure the full status of citizenship and human rights of disabled people;
- Perspective emphasises the individual and collective responsibility of disabled people, united by the common experience of oppression;
- Disablement is essentially concerned with oppression, individual rights and choice, social change and empowerment and politics.

Limitations

- Disability is perceived as a purely medical phenomenon, giving no recognition to the social, economic and political environment in which disabled people live:
- Historically, undue power and influence has been given to the medical and para-medical professions in deciding how disabled people should live, invariably making decisions which are of a purely administrative, not medical nature.

- Perspective assumes disabled people to be a collective homogeneous entity, united by their common experience of oppression;
- No allowance is given to the fact that individual disabled people can exercise “agency”, thereby devising different strategies to achieve similar outcomes:
- Not all disabled people consider themselves to be “oppressed” in the manner envisaged by the disability movement;
- The causal link between how society actually “disabled” people with impairments remains unclear, and cannot be easily measured;
- Model takes insufficient account of those with cognitive impairments.

This section will also attempt to highlight those factors, which can be drawn from the analysis presented above, which policy-makers and practitioners working in the field of should be aware of when designing and implementing community-based disability services in the South Indian context. This paper has attempted to examine the cultural understandings and interpretations of disability and impairment in a society such as is found in South India. Before assessing the relative merits of the medical and social perspectives of disability, it is important to emphasise two fundamental points that underpin what follows. Firstly, it has demonstrated that the lives of disabled people within South India are indeed complex and imbued with culture, as they are in all societies.
Therefore, it is maintained that it is not possible to fully understand the complexities and dynamics of what it is to experience disability within a particular society without gaining some comprehension what the broader social, economic and political context of a particular society in which disabled people live. What is means to have an impairment and experience disability is therefore, by implication, culturally defined and will vary between societies. For example, consider the case of an individual who has dyslexia. In a predominantly rural agrarian society, such as South India, the fact that an individual cannot read and write is not likely to inhibit their ability to work and participate fully in local community life. However, a person who is dyslexic living in a western-based society is more likely to be unemployed, for in a myriad of ways, in order to function within society, there is a prerequisite for an individual to be literate. Reference has already been made to the UK Government’s 1999 Labour Force Survey which found that the majority of those with learning difficulties were unemployed and in receipt of state benefits (Department for Education and Employment, 1999).

Secondly, in agreement with evidence presented from other developing countries, this research has shown that there is indeed a symbiotic relationship between poverty and disability. The presence of an impairment increases the probability that a disabled person will be poor, for the evidence suggests that the majority of disabled people will have a lower standard of education and are more likely to be unemployed or under-employed, than their able bodied counterparts. Also, the need for additional expenditure for basic medical treatment and rehabilitation services will place additional economic strains upon the family, particularly within a rural context. Furthermore, within developing countries such as India, those who are poor are more likely to be susceptible to the onset of ill-health and impairment. The poor are more likely to live in areas characterised by over-crowded housing, inadequate sanitation and so forth. Furthermore, within subsistence economies, the poor invariably have insufficient land to grow food that meets their basic dietary needs. Within such families, babies have an increased likelihood of being underweight and are more prone to illness and disease (Elwan, A; 1999:16).
The evidence presented has demonstrated that an understanding of disability in South India, as perceived by disabled people and their families specifically interviewed for research and corroborated by secondary sources, is indeed complex and cannot easily be understood in terms of either the medical or social perspectives. Both perspectives have elements which provide some pertinent insights and understandings regarding the lives of disabled people, but neither provides a complete, coherent and intellectually convincing explanation. On the basis of the evidence presented within this thesis, the dualism between disability and impairment (as defined with the World Health Organisation’s 1981 classification) traditionally maintained by disability activists and the disability movement, whereby disability has nothing to do with the body, cannot be sustained. As has already been explained, both of these terms are socially and culturally defined.

The findings drawn from this research suggest that, within the South Indian context, those with different impairments will experience the pejorative manifestations of disability in a multiplicity of ways. Some impairments, such as cerebral palsy, occur at or around the time of birth, and the individual will have to live with the consequences of their impairments for the entirety of their lives. Others may acquire their impairments, sometimes quite suddenly through an industrial, agricultural or road accident. The onset of an impairment caused through an accident will inevitably be a tremendous shock, and all previously held social norms and social mores are likely to be questioned. In such a situation, the person has the potential to draw upon their previous experience of education and social networks in ways that will assist them in adapting to the new situation. Thus, it is posited that a person who has acquired an impairment during adulthood is actually in an ambiguous position vis-à-vis disability and impairment. If indeed the onset of old age is perceived as an impairment, then it raises questions regarding the distinction drawn between normality and abnormality by the medical perspective.
Furthermore, the understanding of disability and impairment from a South Indian perspective raises questions regarding the universal applicability of the medical perspective of disability. A medically orientated and technocratic etiology of impairment does not provide a coherent and convincing explanation, since generally, western understandings of disability fail to appreciate the relevance and significance of religious conceptualisations. Alternatively, perceiving phenomena such as old age, swelling, pain and even medical intervention itself as impairments questions the distinction drawn between impairment and disability as usually posited by the social perspective.

The importance placed upon participating in the local economy through engaging in employment, and perhaps more importantly, being demonstrably seen to do so, suggests that to some extent at least, the tenets of the social perspective of disability do have credence and validity within the South Indian context. It will be recalled that the historical materialist variant of the social perspective (Oliver, M. 1990) postulates that disabled people have been systematically excluded from participating in society, primarily through the manner in which society has been economically structured, and the negative social attitudes that disabled people have thereby encountered. It is possible to provide evidence that this is sometimes the case in India, since the social standing and status that a disabled person has is indeed largely contingent upon gainful employment. This theory has only partial validity within the Indian context. It is premised upon the notion that disabled people are unable to work because of the way in which society is structured. Clearly, this is not true within India, since the majority of disabled people have the appropriate skills to be engaged in some form of employment. However, there are a small proportion of disabled people who are unable to work, because the severity of their impairment precludes them from engaging in economic activities. In such instances, what is needed is an adequate social welfare system, rather than employment training programmes.
The primacy given to the importance of gaining access to employment, coupled with the petty corruption of local
government officials, highlights the importance of economics in any discussion of disability and concurs with the
underlying tenets of the social perspective. It is readily apparent from the findings of this thesis that the most
important issue that disabled people face in a society such as South India is the need to be gainfully employed.
However, although the social perspective does indeed have a degree of explanatory power within India, it is by
no means totally persuasive, and does not account for all the facets of the complex lives that disabled people
encounter. The issue of marriage and family is a case in point.

The findings and inferences drawn from this paper also raises questions regarding the validity of the individualistic
rights-based approach to empowerment as espoused by the radical disability movement. The vast majority of
respondents thought that it was the general case that all major decisions, notwithstanding the presence or absence
of disability, were made in the context of the family. However, in the case of disabled people, it was thought that
on occasions they were given more latitude and freedom in the decisions that they could make for themselves. It
was considered that the presence of an impairment to some extent liberated disabled people from the commonly
held norms or social expectations that underpin the social mores of Indian society. It was also thought that
disabled women were more restricted in the decisions they could make for themselves than were disabled men.

The demographic characteristics of disabled people in the three villages analysed in the Erb and Harris-White
study are of interest, for they highlight a number of issues regarding the provision of community-based disability
services. The number of disabled children - ie., those under the age of 14, was very low indeed- approximately
two per cent of the non-adult population. However, the National Sample Survey Organisation (1991) estimated
that approximately 20 per cent of rural disabled individuals were children. Erb and Harriss- White were disturbed
by their own research statistics for incidence of childhood disability for two reasons. Firstly, it implied, when
comparing national statistics with the profile of disability found within Thammanur Main Settlement, that many disabled children were not reaching adulthood. Secondly, it implied that the onset of disability occurs during adulthood. These implications warrant further consideration.

This research has also shown the importance of gender when discussing attitudes towards disability with a society such as found in South India. From both primary and secondary evidence, it is clear that the quality of life, and even the chance of survival, are far worse for women than for men. The severity of impairment has to be far more accentuated for women than for men before it is socially acceptable for women to stop providing domestic support, thereby making a positive contribution to the household. Furthermore, men are more likely to receive basic rehabilitation services, and have more financial resources spent on these services than are women. These findings and the some of the implications that these have for disability service provision are summarized in Box 2 overleaf.
### Box 2  Understanding Disability in a South Indian Context

| Experiences | # Disabled people encounter a multiplicity of attitudes ranging from the possession of god like powers to being ostracised, pitied, and shunned by the local community;  
|             | # The key determinant of deciding who is disabled is contingent upon whether an impaired individual is able to be engaged in gainful employment, either through open employment, or through making a positive contribution within the domestic household;  
|             | # The key priorities for disabled people is to find employment and get married. The provision of medically-based rehabilitation services are of secondary importance in relation to these two key objectives;  
|             | # There is a gender bias vis-à-vis the provision of rehabilitation services. It is more likely that men will receive and benefit from such services than women. Also, the severity of an impairments needs to be greater for a woman and a man, for it to be socially acceptable for that individual to be excused from making a financial contribution within the domestic household.  
| Attributed Causes | # The etiology of impairment is often attributed to religious understandings - in particle the Hindu notion of karma. Thus, disability is to result of the moral failure of the individual or the sins of their ancestors;  
|             | # Sometimes, disability is attributed to witchcraft or black magic;  
|             | # Western-based understandings of disability can also be found in India, which are primarily premised upon the application of medical science.  
| Key Problems | # The widespread belief is that disabled people are second-class citizens within their own society;  
|             | # The gender-bias in the provision of rehabilitation services.  
| Key Priorities | # The need to ensure that rehabilitation services genuinely meet the explicitly stated needs and aspirations of disabled people;  
|             | # To ensure that, as far as possible, disabled people are engaged in gainful employment, thereby making a contribution to the domestic household;  
|             | # To address the gender bias in the provision of rehabilitation services;  
|             | # For NGOs to run disability-awareness programmes, dispelling some of the negative connotations associated with disability.  

**REFERENCES:**


