

**Social Factors Influencing the Education of
Physiotherapists
Around
Disability in Bangladesh**

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of Philosophy**

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**The candidate confirms that the work submitted is her own and that appropriate credit has been
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Abstract

Social Factors Influencing the Education of Physiotherapists around Disability in Bangladesh

Background

Professions such as physiotherapy are challenged to respond to changes occurring internationally in approaches to disability. Correctly theorising disability enables appropriate responses to emerge, which address issues important to disabled people and thus enhance service effectiveness.

Purpose

The purpose of the research was to utilise evidence drawn from user perspectives around disability in Bangladesh, to inform the theoretical underpinnings of professional physiotherapy education and the training of related healthcare workers.

Sample

Data from service users were collected using twenty-seven individual semi-structured interviews with disabled people who had accessed therapeutic services within the previous year. Data from provider groups were collected using thirty-six individual interviews and focus group discussions.

Design

A qualitative research design was used.

Process of analysis

All final transcripts were in English and a thematic analysis was undertaken in three stages. User group findings were firstly analysed and then compared systematically with each provider group analysis. Comparisons generated usable knowledge which informed theoretical underpinnings around disability.

Findings

Theoretical underpinnings around disability were informed by an individual model of disability in five out of six courses preparing workers for this field in Bangladesh. One course only was underpinned by a social model of disability. This training was based on a strategic, rights-based, development approach to disability. Interventions from this group showed the greatest congruency with perceived needs of service users. A number of changes in course content were identified which will facilitate greater congruency with service user needs in physiotherapy and related healthcare worker preparation. These include the introduction of a fourfold typology of disability, knowledge of practice epistemology, an understanding of professional socialisation, a greater awareness of collectivist value systems and a strategic response to gender stratification.

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Acronyms and Abbreviations

ADA	Americans with Disabilities Act
ADCD	Asia-Pacific Development Centre on Disability
ADD	Action on Disability and Development
AIFO	Association Amici di Raoul Follerau
APSO	Agency for Personnel Services Overseas
APTA	American Physical Therapy Association
BCODP	British Council of Organisations of Disabled People
BDT	Basic Developmental Therapy
BHPI	Bangladesh Health Professions Institute
BMF	Biwako Millennium Framework
BPA	Bangladesh Physiotherapy Association
BPKS	Bangladesh Protibondi Kallyan Shomity
CAHD	Community Approaches to Handicap in Development
CBR	Community Based Rehabilitation
CDD	Centre for Disability and Development
CHDRP	Community Handicap Disability Resource Person
CRP	Centre for the Rehabilitation of the Paralysed
CRPD	Convention on the Rights of Persons with Disabilities
CRT	Community Rehabilitation Technicians
CSID	Centre for Services and Information on Disability
CSP	Chartered Society of Physiotherapy
DAR	Disability and Rehabilitation Programme at WHO
DFID	Department for International Development
DIDN	Disability Information Dissemination Network

GO	Government organisation
HI	Handicap International
ICF	International Classification of Functioning Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICRC	International Committee of the Red Cross
ILO	International Labour Organisation
ISEP	International Society of Physiotherapy Education
MJF	Manusher Jonno Foundation
NFDDP	National Foundation for Development of the Disabled Persons
NFOWD	National Forum of Organisations Working with the Disabled
NGO	Non-Governmental Organisation
NITOR	National institute of Traumatology and Orthopaedic Rehabilitation
PAHO	Pan American Health Organisation
PDRP	Physical Disability Resource Person
SHIA	Swedish Organisations of Disabled Persons International Aid Association
UAGIC	Upazila Action Group Implementation Committee
UDPDC	Upazila Disabled People's Development Councils
UN	United Nations
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UPIAS	Union of the Physically Impaired against Segregation
WCPT	World Confederation for Physical Therapy
WHO	World Health Organisation

INTRODUCTION

'AMAR PANT CHIRREY GIETCHE' (MY PANTS ARE TORN)

This chapter introduces the structure of the thesis and gives the background to the study, briefly describing the disability scenario in Bangladesh and the key disabled people's organisations there. The introduction of physiotherapy education and training is historically located.

0.1 Background to the Study

In 1991, whilst working as the only physiotherapist in a general hospital and a Leprosy hospital to which it was linked in Bangladesh, I was invited to be the examiner for the first group of Leprosy Physiotherapy Technicians ever to be trained in Bangladesh. The skills being examined included the ability of candidates to identify nerve damage caused by the leprosy bacteria. Each candidate's task on that day was to identify the level of nerve damage accurately and devise an appropriate programme of physiotherapy.

As examiner, I watched one of the candidates begin his assessment. His patient was a child around nine years old who was already displaying signs of advanced nerve damage. Presented with such a high level of visible impairment in a child, there was much he could do and suggest. An effective worker has lots to offer in terms of helping to minimise and prevent further damage in leprosy, a disease where visible deformity is often linked to stigma.

His first question to the small ragged child standing in front of him was 'What is the problem?' The child turned slightly and pulled on his short pants displaying a large hole and replied directly 'Amar pant chirrey gietche!' (My pants are torn!). As far as the child was concerned this was *the* problem. This incident epitomised for me the problem this research seeks to address. Both the technician and myself were looking at the child 'with a medical gaze,' (Foucault 1963) focused only on the child's physical deficits. The real problem staring at us was on a much wider scale and related to issues such as poverty and discrimination. Oliver (1996, p.36) suggests that the professions allied to medicine are trapped in a set of social relations which they are not trained or

equipped to deal with. As experts, when confronted with the social problems of disability, they cannot admit that they do not know what to do. I was confronted by this uncomfortable truth. Apart from hastily arranging the purchase of two new pairs of pants for the child I did not know what to do, and pondered on why this was so. The research reported in this thesis explores this whole area of 'equipping' physiotherapists and related healthcare workers in Bangladesh so that they may seek out some answers to the issues they are confronted with.

0.2 Disability in Bangladesh

Bangladesh is located in the largest river delta in the world, facing the Himalayas in the North, bordering India in the West, North and East, Myanmar in the South-East, and the Bay of Bengal in the South. Its geographical position makes it highly susceptible to natural disasters and flooding. It currently ranks as the world's foremost disaster-prone country.

A problem analysis of the situation for disabled people in 2005, led by the Centre for Services in Disability (CSID), described overlapping contributory factors. Bangladesh is one of the most densely populated countries in the world. Statistics on the prevalence of impairment in Bangladesh were debatable, as widely differing figures were being reported. Figures were thought to be between 7 and 14 million disabled people in a population of over 140 million, 80 percent of these disabled people living in rural areas. There was little or no development assistance available to them. Therapeutic services and the availability of assistive devices were extremely limited. Professionals such as physiotherapists were few in number and posts were unavailable to them in the government hospitals. Many disabled people lacked the skills to be involved in economic activities and employers were reluctant to employ them due to their ignorance about impairment, negative attitudes, and inaccessible work places. There were limited opportunities to study at educational institutions. The majority of disabled people were unaware of their fundamental rights. Poor nutrition, dangerous working and living conditions, limited access to health care, poor hygiene, bad sanitation, inadequate information about causes of impairment, and natural disasters all contributed to their life experiences. Additionally almost 70 percent of disabled people were unable to seek medical or rehabilitation assistance due to economic hardship (Khandaker 2005).

The timeliness of this study is underlined by the observation that, in the last ten years, the situation in Bangladesh appears to have been in transition. A paradigm shift from a charity-based approach to a developmental and rights-based approach towards the empowerment of disabled people has started in Bangladesh. Remarkable changes are being precipitated in the field of disability. These are starting to take effect both nationally and in the wider region. Three key organisational players have emerged, enabling disabled people to have a collective voice and representation to the government, and promoting research and training in this field. These organisations are: the National Forum of Organisations Working with the Disabled (NFOWD), the Centre for Disability in Development (CDD) and the Centre for Services and Information on Disability (CSID).

NFOWD was established in 1991 and works in three areas; raising national level awareness and sensitisation on disability issues, policy and advocacy and coordination amongst its members. Its principal working relationship is with the Government of Bangladesh. In 2006 this resulted in the approval of a government National Action Plan on Disability (Khandaker 2005). Beginning with only 22 member organisations, NFOWD has grown to 325 organisational members spread across 61 districts (out of 64) in the country (Khandaker 2011). There are now (in 2011) approximately 50,000 NGOs working in development in Bangladesh; about 400 of these are working in the disability field (Khandaker 2011).

The second key organisation, the Centre for Disability in Development (CDD) is an NGO dedicated to development of quality human resources and information on disability. CDD was one of the participating organisations in this research. It provides a basic training in physiotherapy skills as part of a wider strategy to address disability working at primary, secondary and tertiary levels. It has been offering training programmes to development organisations since 1997. The third organisation, the Centre for Services and Information on Disability (CSID) began playing a major role in disseminating information on the progress of disability work at national and international levels in 1999. These organisations have been instrumental in highlighting Bangladesh on the international disability and development stage.

Following the targets set for Asia around self-help initiatives in the Biwako Millennium Framework (ESCAP 2002), and a number of Disabled People's organisations (DPOs) are

also emerging in Bangladesh. These are mostly supported by two large NGOs, namely: Action on Disability and Development (ADD) and the Bangladesh Protibondhi Kallyan Shomity (BPKS). Both organisations are involved in the co-ordination and development of skills and leadership training for disabled people, and encourage them to come together in self-help groups. While the small DPOs look mostly into their own micro-level issues, with experience and gradually gathering maturity, they are also beginning to look at macro-level issues and are contributing to a national disability development movement.

In 2004, ADD organised a national convention of about 5,000 disabled people in Dhaka. Attending this conference gave me the stark realisation that I was witnessing what appeared to be a remarkable social change within the field of disability in Bangladesh. Despite almost ten years experience of working in Bangladesh, first as a hospital-based physiotherapist, and then as a physiotherapy educator, I had not been aware of this before. It was, however, clear to me that these developments were not impacting the educational initiatives for physiotherapists with which I was closely involved. The considerable efforts being made to introduce professional physiotherapy education were taking place with little reference to major changes occurring in the wider disability field. This separation became an important aspect of the research for this thesis, alongside other experiences such as the examiner incident described above, and created in me both an intrigue and a determination to unravel an understanding of the emerging dichotomy before me. My motivation in being in Bangladesh was to contribute to the development of services that addressed the concerns of disabled people. There seemed to be something of great importance in what I was witnessing, which was relevant to professional education of physiotherapists and to other workers similarly engaged.

Leavitt (1992) noted that in countries where physicians and clinics are rare, rehabilitation services may be non-existent. In 1989, when I first arrived in Bangladesh there were just six physiotherapists in the country and there were no occupational therapists and no speech therapists. A previous attempt had been made to educate physiotherapists and occupational therapists after the war of liberation in 1971, but of the 25 who qualified, all but 4 left the country (Taylor 2006). Professional training of physiotherapists was reintroduced in 1994. By 2004, when this research was

conducted, there were around 500 physiotherapists who were either being educated as physiotherapy professionals, or were newly qualified. Together these represented the emergence of an embryonic professional group. However, lack of available posts in government hospitals for qualified physiotherapists was limiting access to these services. Private fee-paying hospitals were more likely to employ the small numbers of graduates available, but these services were financially inaccessible to a large majority of the population. Private physiotherapy practice was also unaffordable for most people. A further factor restricting access to physiotherapy services was the beginning of a steady exodus of qualified physiotherapists from the country, in a repeat of history.

Education of physiotherapists to professional level is advocated by the World Confederation for Physical Therapy (WCPT), in order to ensure the attainment of high standards of therapeutic intervention. The recommendation is that education for entry-level into this single profession, should be based on university level studies for a minimum of four years. These should be independently validated and accredited as being at a standard that affords graduates full statutory and professional recognition (WCPT 2009). WCPT has supported many member organisations including Bangladesh in their attempts to obtain ministerial support for degree-based programmes, and encourages the growth of autonomous practice (WCPT 2010).

Alongside professional education in physiotherapy in Bangladesh, four other approaches to training personnel on shorter courses had also been introduced. These all provided physiotherapy as a part of their role, and could be loosely described as courses for related healthcare workers. Two of these approaches were based on Community Based Rehabilitation (CBR) and trained 'mid-level' workers. Two others were focused on specific impairments i.e. leprosy physiotherapy technician training and the training of developmental therapists. My experience in Bangladesh and elsewhere meant that I was familiar with three out of four of these alternative approaches. My employing institute in Bangladesh had begun training one type of worker for community-based rehabilitation, I had worked in the leprosy field for four years alongside a leprosy physiotherapy technician, and I had previously assessed a project for disabled children in India which utilised developmental therapists. The very small numbers of people engaged in these initiatives meant that it was possible to

know all the professional physiotherapy educators and all the key personnel involved in alternative training initiatives. From this vantage position I was struck by the fact that, prior to introducing these lengthy professional courses, there had been no assessment of the contribution being made by these other types of workers.

A number of influences were significant in the decision to prioritise the little-heard voices of disabled people themselves in this research enquiry. These included my studies in the discipline of Disability Studies at the University of Leeds. Prior to this whilst completing my Master's degree I had encountered a number of definitions of quality. These included 'Satisfying customer requirements' (Juran et al 1974; Feigenbaum 1983) and 'Fitness for purpose' (Harvey 1995). Definitions of service quality often use the words 'perceived service quality' (Cuganese et al 1997) to emphasise that it is service quality from the customers' perspective that is important. Theoretically, the 'customer' specifies service requirements. Davidson et al (1997) demonstrated that service delivery can only be effective if it is addressing the problems perceived by service users.

Applying these principles to disability services in Bangladesh required an understanding of user perspectives within this context. A mismatch in interpretation of the problem could lead to a mismatch in services designed to address it. Professional educators are in a key position to guide the socialisation process of their students and ensure that the role they have benefits the service user. However, to do this, their knowledge needs to be underpinned by a sound theoretical base. The question of where that knowledge is drawn from in new contexts, becomes an important consideration. Hammell and Carpenter (2004, p.24) maintain that theory developed in the absence of clients' perspectives provides an unstable base from which to inform client-centred practice. This highlights the importance of listening and learning from disabled people.

These ideas located professional socialisation processes, sources of knowledge, the influence of culture and the transfer of Western ideas, as key themes of interest in this inquiry.

0.3 Research Questions

There are three main research questions in the study. The findings from the first two questions are intended to inform the third.

1. What characteristic knowledge, beliefs and expectations around disability typify users of therapeutic services in Bangladesh?
2. What beliefs do student physiotherapists and related healthcare workers hold around the needs of disabled people and their own particular role in providing intervention, and what is influencing this perception?
3. Are there identifiable adjustments in professional education and training of related healthcare workers around disability that might be beneficial for disabled people in this social context?

0.4 Structure of the Thesis

The study is divided into nine chapters. The first three chapters 'set the scene' for the study.

Chapter 1. The first main topic of the thesis, disability, is the subject of the first chapter. This chapter concerns definitions around disability and conceptualisations of disability in both minority and majority contexts. This chapter debates the importance of understanding disability and impairment in national contexts and cultures.

Chapter 2 considers disability in relation to context with particular reference to Bangladesh. It examines issues of relevance to the study including oppression, marginalisation, and identity. Compounding factors influencing behaviour in South Asian communities are discussed. These include religious and cultural beliefs, family and kinship systems, and collectivist value systems.

Chapter 3 is concerned with the education of professional physiotherapists and the training of related healthcare workers that have emerged in Bangladesh and other majority world settings. It examines different models of practice and the sources of knowledge which underpin clinical practice. The process of professional socialisation is discussed. Traditional emphases in professional physiotherapy education are critiqued in this chapter. The rationale for alternative approaches to service delivery and the dilemmas these pose for professional education are then presented.

Chapter 4 describes the way in which the methodological decisions in this research were made. It describes how the research strategy was chosen and how the data generation and analysis were implemented, reflecting also on the experience of fieldwork in Bangladesh and some of the contingencies and limitations involved.

Chapter 5 presents the way in which disabled participants in this study perceive their experiences. It reports on the perspectives they hold with respect to interventions made by physiotherapists and related healthcare workers, and the expectations they have of the society in which they live. It particularly seeks to establish an understanding of the lived experience of disability in Bangladesh.

The next three chapters report on the perspectives held by different 'provider' groups around the needs of disabled people and their particular role in meeting these needs. Findings for each group are compared with systematically with 'user' perspectives and areas of congruence identified. Implications for training and education are discussed.

Chapter 6 reports on two initiatives to train workers based around single impairment groups, namely, people with leprosy and children with developmental problems.

Chapter 7 identifies the roles and perspectives of two groups of Community-Based Rehabilitation workers whose practice is informed by very different conceptualisations of disability.

Chapter 8 seeks to identify how students being educated as professional physiotherapists perceive their role within the healthcare system. This chapter also examines the professional socialisation process occurring and indicates the focus of attention of this emerging group.

Chapter 9 draws conclusions from the study. It argues for changes in educational policy and practice in Bangladesh. Points of relevance to comparable contexts elsewhere are discussed. The limitations of the study are noted and areas for further research are identified.

Chapter One

1. DEFINING DISABILITY AND IMPAIRMENT IN MAJORITY AND MINORITY CONTEXTS

1.0 Introduction

The main theme of this thesis concerns the education of physiotherapists and related healthcare workers around disability in Bangladesh. Priestley (2003) stressed that the way disability is learnt about and understood affects the way people respond to disabled people in the society. This applies both to the population in general and to the workers in the field of disability. Definitions and conceptualisations of disability have however been the subject of considerable academic and political debate, particularly in the last three decades. Bajekal, Harries, Breman and Woodfield (2004, p.53) declared for example, 'There is no single, accepted definition of what disability means'. The first chapter engages with the main debates and conceptualisations of disability as a key theme underpinning this thesis. It provides a critical account of the important debates around current definitions of disability drawing extensively on key thinkers in the discipline of Disability Studies.

This chapter is divided into five sections. Following a brief note on terminology, section one begins by identifying the definition of disability used in legislation relating to disability in Bangladesh at the time of this research. Section two defines the concept of a 'model' of disability and examines the first of two specific models of disability which have dominated the literature, i.e. an individual model of disability. Section three then examines the second of these, a social model or social interpretation of disability. Section four focuses on the more recent proposal of an interactional model of disability which explains disability in terms of an interaction of individual and structural factors (Shakespeare 2006, p.55). Section four also discusses the International Classification of Functioning Disability and Health (ICF) (WHO 2001). Section five then presents a fourfold typology of disability offered by Priestley (1998) encompassing the different conceptualisations of disability and concludes with an explanation and justification of terminology around disability adopted in this thesis. Several of the topics covered in chapter one are expanded upon in later chapters.

1.1 Section One

1.1.1 Terminology

The term 'majority world' is used in this thesis to denote developing countries, the 'South', or the 'Third World' following Stone's usage by Stone (1999a, p.4) in her treatise on Disability and Development. The term 'minority world' denotes developed nations, the 'North', and industrialised countries. The term 'majority world' or 'the South' indicates the world inhabited by the vast majority of the world's people who collectively access a fraction of the world's wealth and power. The 'minority world', 'the North', indicates the richest countries in the world in which a minority of the world's population live and utilise a major share of global resources. Stone highlights the fact that although the terms 'majority world' and 'minority world' cannot strictly be defined purely by geographical notions of wealth and power, as there are pockets of deprivation in countries of the North and examples of great wealth in countries of the South, there is nevertheless a recognition that most disabled people live in the majority world and that they do so in poverty and without access to appropriate support. (Stone 1999a, p.4). According to Helander (1993) this figure is approximately 80% with 60-70 % of these living in rural areas.

1.1.2 The Disability Welfare Act of 2001

The legislation around disability in Bangladesh in 2004 is used as a starting point to reflect governmental perspectives and approaches towards disability in Bangladesh. Priestley (2001) drew attention to the preponderance of minority world contributions in the literature around disability:

'The academic literature of disability studies consistently privileges minority world accounts (especially those from Western Europe and North America)... Majority world perspectives do exist; however, such contributions are rarely cited within the academic literature of disability studies' (Priestley 2001, p.3).

In the context of this thesis, which is focused on the personnel working in Bangladesh, it is important to examine perspectives originating in majority world accounts alongside these minority world accounts.

In Bangladesh the Ministry of Social Welfare, in association with the National Forum of Organisations Working with the Disabled (NFOWD) initiated draft legislation on disability-related issues in 1996. This legislation was formally enacted in April 2001 and

is known as The Disability Welfare Act of 2001. Until the last decade disability has had a very low national profile in Bangladesh, and The Disability Welfare Act of 2001 was hailed as a landmark as it was the first and most significant piece of legislation around disability issues in the country.

The following functional English version was translated by the National Forum of Organisations Working with the Disabled (NFOWD 2001). In this legislation, disability is defined in terms of biomedical deficiency, and is seen as a characteristic of the individual, not of the society. The direct quotation is given as it appears:

'Disability means any person who is physically crippled either congenitally or as result of disease or being a victim of accident, or due to improper maltreatment or for any other reasons became physically incapacitated or mentally imbalanced, and as a result of such crippledness or mental impairedness has become incapacitated, either partially or fully; and is unable to lead a normal life.' (NFOWD 2001)

The adoption of a biomedical approach to the definition of disability was not unanticipated in such a post-colonial context, where the establishment of a national healthcare system had been strongly influenced by Western medical professionals who also approached disability as an individual characteristic.

The importance of the legislation was that it signalled the adoption of a clear stance on equality adopting a rights-based approach to disability in Bangladesh for the first time. It focused on improving the social situation of such persons and includes legislation relating to the following areas: protection of rights of 'persons with disabilities', equal opportunities for participation in education, training, employment opportunities, tax relief and subsidies, exemption of custom duties for 'persons with disabilities' and their families on imported items and assistive devices, elimination of architectural/logistical barriers, dissemination of information on legislation and prohibition of abuse and neglect.

The move towards establishing rights by law for disabled people in Bangladesh appears to have been precipitated by a number of factors. These include government participation in international forums concerning disability, developments which have already taken place in neighbouring Asian countries and lobbying by informed national bodies within the country.

'According to WHO's Expert Committee data, some 10 per cent of the population are victims of disability in developed and developing countries...Laws aiming to ensure equal opportunities... have been enacted in India in 1995, in Pakistan in 1981, and in Sri Lanka in 1996.....The present Government is committed to the welfare of the disabled community or any other disadvantaged section of the people. Thus, the Government is proposing to pass this law called Bangladesh Persons with Disability Welfare Act-2001' (Disability World 2001).

The preamble to the legislation also indicated that disabled people were considered to be a disadvantaged group in the society deserving of welfare.

1.2 Section Two

1.2.1 Models of Disability

In thinking about conceptualisations of disability, Swain et al. (2003, p.31) utilised the idea of a model in understanding the situation:

If more than one set of beliefs about a particular phenomenon exist within a society, the explanatory model of the most powerful group will be validated as true and superior to the explanatory models of others.

Llewellyn and Hogan (2000) define a 'model' in the following way:

A model represents a particular type of theory, namely structural, which seeks to explain phenomena by reference to an abstract system and mechanism.

They point out that a model in itself may not constitute an explanation but may help to generate one. Oliver suggests a model is 'a practical tool not theory, idea or concept' or it shows 'ways of translating ideas into practice' (Oliver 2004, p.19). Coleridge defines a model as 'a framework by which we make sense of information' (Coleridge 1993, p.71).

A number of different 'models' of disability have emerged, two of which have dominated the literature in disability studies i.e. the individual and the social models of disability. Other models and explanations of disability exist but though important have been less salient in recent literature. Coleridge (1993, p.71) for example makes use of the 'traditional model' of disability with particular reference to developing countries. He describes this as a construct created by religion and culture in any society. Priestley (1998) points out that a separate model is unnecessary as the social model includes both these idealist explanations of disability.

Models of disability thus represent a type of theory which attempts to explain disability by reference to an abstract system and mechanism. The next section will explore the individual model of disability.

1.2.2 An Individual Model of Disability

Oliver (1983) suggested the term 'individual' model contrasting it with a 'social' model of disability. As the name suggests this model presents an understanding of disability that is individualistic where disability is viewed as product of individual differences in biology. In this model, disability is considered to be a result of a physical condition and is intrinsic to the individual. There is no conceptual separation between impairment and disability, both reside in the body, hence the expression 'persons with disability'. Secondly, functional limitations or psychological losses which are assumed to arise from disability cause the problems associated with it (Oliver 1983, p.32).

The term 'individual model' is commonly used interchangeably with the term 'medical model' despite the fact that Oliver has stressed that there is no such thing as a 'medical model of disability'. His contention is that medicalisation¹ is 'one significant component' of an individual model of disability (Oliver 1996). Nevertheless, the idea of a 'medical model' has been advanced, developed and extensively quoted by several other authors. In this text, writing referenced will use same term as the source quoted. Mishler et al (1981) and Pratt (1989), for instance, maintain that a 'medical' or 'biomedical model' is made up of a key set of assumptions around issues relating to the working of the human body. These include a specific aetiology as the cause of disease, generic disease, scientific neutrality and sequential progress in knowledge acquisition, dualism and reductionism. They maintain that the concept of 'normality' is fundamental in these assumptions, deviations from which are abnormal or deviant. Thus, according to these writers, a body-mind dualism principle is enshrined in the so-called 'medical model'. Descartes, the French philosopher (1596-1650), had proposed this metaphysical split in the seventeenth century and its dominance in the Western

¹ Medicalisation is defined as a social process through which a human experience or condition is culturally defined as pathological and treatable as a medical condition. It is sociologically significant because it vests authority in the medical profession for defining appropriate social responses to various conditions (Johnson 2000, p.190).

medical traditions became evident in the development of separate professions dealing with mind and body.

The emergence of the 'Medical model of disability' is thus closely linked with the development of 'modern' medicine in the 19th century, a development which enhanced the role of the physician in Western society. Because impairments were increasingly considered to have medical origins, there was a strong expectation that individuals with impairments needed intervention from medical professionals. Included in this model are both medical (or biological) aspects of disability and psychological aspects concerning identity and negotiation of social role.

Oliver (1996) suggested that an individual model of disability tends to regard disability as a personal tragedy. Barnes and Mercer (2003) maintain that the involvement of the medical profession in disability has been central to the legitimization of this approach and that medicalisation has emerged as a key aspect in the social control of disabled people by supplanting more religious and traditional approaches. They write:

'While people in early modern societies consulted a range of lay and "medical" practitioners about their health and general well-being, by the nineteenth century an orthodox medical profession had overturned this pluralism in healing practice' (Barnes and Mercer 2003, p.27).

They maintain that result of these changes in Western society pre-1960s was the generalised equating of disability with the idea of flawed minds and bodies. This encompassed those who were 'crippled' or were confined to wheelchairs and included 'victims of conditions such as cerebral palsy, or those suffering from deafness, blindness, mental illness, or mental handicap' (Barnes and Mercer 2003, p.1). Moreover, the main consequence of this identity was the following:

'The individual's impairment or abnormality necessitates dependence on family, friends and welfare services, with many segregated in specialised institutions. In short, disability amounts to a "personal tragedy" and a social problem or "burden" for the rest of society' (Barnes and Mercer 2003, p.1).

Barnes and Mercer (2003) point out that extending debates around definitions of impairment and disability beyond English-speaking countries into majority world contexts is problematic, because ways of perceiving health and ability differ markedly across the cultural systems of the majority world. Therefore, these key concepts are not easy to translate into other languages and cultures. Stone (1999b) for example

maintains that in Chinese culture, mind, heart and body are treated as indistinguishable and that body-mind therefore have to be considered as a single entity in contrast to the dualism of Western biomedicine.

Pfeiffer (1998) maintains that the individual model of disability places an individual with impairment in a sick role. This then permits qualified professionals to make decisions about the quality of that person's life (Pfeiffer 1998). In the UK until recently most disability policy issues were regarded as health issues, and physicians were regarded as primary authorities in this policy area. An example of the continuing powerful influence of the medical profession in the UK is shown in the assessment of capability for work of people deemed to 'have a disability'. The Personal Capability Assessment (Directgov 2011), an assessment of the level of incapacity for work is based on physical and mental health examinations by doctors or other healthcare professionals, who are authorised to certify whether or not a person is capable of work.

In UK law, disability is defined in terms of the effects of impairment on day-to-day activities in the Disability Discrimination Act of 1995:

A person has a disability for the purposes of the Act if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to day activities (Disability Discrimination Act 1995, in Doyle 1996).

This model thus links the cause of disability with individual impairment.

1.2.3 Questions Around the Validity of the 'Medical Model'

Whilst welcoming appropriate medical intervention to eliminate impairment or reduce its effects, medicalisation of disability has evoked strong and sustained criticism of the power differentials in the relationships thus produced between professionals and disabled people. Shakespeare (2006) criticised the way that technical language has been used by medical professionals to control and exclude and claimed that the historic exclusion of disabled people from the professions fuelled a lack of understanding and mutual respect. Shakespeare highlights the fact that having an impairment, or experiencing the social disadvantages often associated with impairment, makes people more likely to use doctors, therapists and other

professionals. This puts professionals in an important position in the disability field (Shakespeare 2006, p.193).

Christakis et al (2001) discuss illness behaviour and health transition in the developing world. They point out that biomedicine is often highly regarded in the developing world - but not unequivocally:

Cross-cultural data on illness behaviour from situations of medical pluralism in the developing world indicate that both the perceived efficacy of biomedicine and the decision to use biomedical services are highly variable and subject to influence by a number of intervening factors (Christakis et al 2001, p.145).

It is worth noting here that a medical plurality is very much a feature of life in Bangladesh. Although Alam (2005) noted the decline of Ayurvedic and Unani schools of medicine under the impact of British rule, several overlapping systems continue to exist. These include Western allopathic medicine, Ayurvedic and Unani, homeopathy and traditional healers (kobiraj, totka) and folk healers (pir, fakir). In addition to this, community health workers and pharmacy shops which sell allopathic medicines on demand are common. Also it is notable that the sellers at these mostly unlicensed and unregulated retail outlets also diagnose and treat illnesses despite having no professional training (WHO 2008).

Christakis et al (2001, p.145) argue that from the point of view of the patient, modern health services are often seen as no more effective than traditional medicine. They suggest that patient and community preferences for indigenous healing systems often reflect the realities of how biomedicine is practised in much of the developing world. They point out for instance that for many rural and urban poor in the developing world, the pharmacy is the only contact with the Western healthcare system and that practices at these outlets can lead to significant iatrogenesis and inappropriate drug use. All informal providers are deeply embedded in the local community and culture and are easily accessible. They provide inexpensive services to the villagers with occasional deferred payment, and payment in kind is accepted instead of cash (WHO 2008). Although the picture may be more complicated, these observations suggest that any approach preparing personnel to intervene with rural populations must understand local practices and healthcare behaviour and be able to offer something better in order to compete with this multiplicity of providers.

1.2.4 Summary

The notion of an 'Individual model' of disability represents an understanding of disability that is individualistic. Medicalisation is a significant feature of this model and has been a key aspect legitimising the social control of disabled people in Western contexts. Other cultural traditions display quite different understandings of disability (and responses to it) and are underpinned by different philosophical understandings of its nature. A wide range of therapeutic choices is available in Bangladesh including traditional and Western medicines. The perceived efficacy of biomedicine and the decision to use biomedical services is highly variable and influenced by a number of intervening factors such as the accessibility of informal providers to local communities.

1.3 Section Three

1.3.1 The Social Model of Disability

In contrast to an individual model, a social model presents a social interpretation of disability, relocating the problem from the individual to the society. In this model disability becomes the product of society's exclusion of individuals by the way it is organised and functions. It follows that if disability is to be reduced, then it is the society and not the individual that should be the focus of change. In all areas of social life the issue therefore is an attitudinal or ideological one requiring social change, which at a political level becomes a question of human rights. This conceptual framework acknowledges the existence of impairment but rejects the notion that the impairment is responsible for the disability. For this model disability is a political issue.

The birth and subsequent development of a social model of disability emerged from the work of disabled and other academics. It was fuelled by the lived experiences of disabled people located mainly in the minority world and particularly in Britain. Finkelstein's name is closely associated with the establishment of this model even though Oliver introduced the phrase, encapsulating ideas put forward by the Union of Physically Impaired Against Segregation (UPIAS) in the mid 1970s. After Oliver devised the model it was further developed in academic form in the publications of Finkelstein (1980) and Oliver (1990).

A highly significant early contribution to the discussion voicing strong criticism of the conventional approaches to disability was the book 'Stigma, The Experience of

Disability' (Hunt 1966). In this book Hunt challenged the traditional concentration on the effects of impairment and argued that the problem of disability lay in the area of relationship with 'normal' people. He claimed that descriptors such as unfortunate, useless, different, oppressed and sick are commonly associated with disabled people who are consequently set apart from the ordinary because of the challenge they pose within society's value system. This relational perspective highlighted how people with impairment were routinely subjected to widespread social exclusion. His ideas and perspectives, born out of personal experience, fostered a real sense of social injustice. This gradually gathered support and momentum in subsequent debates and discussions culminating in the UPIAS manifesto in 1976 (UPIAS 1976, p.3). The original definition of disability suggested by UPIAS was as follows:

In our view it is society which has disabled physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS 1976, p.14).

UPIAS's analysis of the disabled society was built on a clear distinction between impairment and disability. Although their policy statement, adopted in 1974 and amended in 1976, did not use the terms 'medical model' or 'social model, it did use the term 'social interpretation'. In socio-political terms disability is interpreted as the outcome of an oppressive relationship between people with impairments and the rest of society. This distinction enabled the construction of a social model or 'social barriers model' according to Finkelstein (Finkelstein 1980, p.47). Thus, in the individual model, disability is attributed to individual pathology, whereas the social model interprets it as the outcome of social barriers and power relations rather than an inescapable biological destiny (Morris 1993, p.10). This separation of impairment from disability was further endorsed by schemes advanced by Disabled Peoples International. In separating impairment and disability a commonality was provided with which to address disability as a political issue and 'the social model of disability' became a powerful political tool with which to fight discriminatory practices.

The achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability i.e. discrimination and prejudice (Shakespeare 1992, p.40).

Recognising its potential as a political tool, Hurst and Albert (2006, p.24) highlight its applicability to both majority and minority contexts.

According to this formulation it is not about health or pathology but about discrimination and social exclusion. This in turn leads to fundamentally different policy priorities and choices, mainly around the removal of disabling barriers, as well as a strong emphasis on human and civil rights (Hurst and Albert 2006).

They stress however that this approach can only yield results for disabled people if they are able to organise and lobby effectively as equal members of a civil society. The slogan 'Nothing about us without us' has been promoted by Disabled Peoples International since 1981. This has been used effectively by disability rights activists to capture the idea of disabled people's struggle for human rights, espousing the idea that self-determination is essential for achieving equality. It has helped unite groups from countries throughout the world in a common cause (Hurst and Albert 2006, p.33).

Charlton (1998) described the lived oppression that disabled people have experienced and continue to experience, as a human rights tragedy of epic proportions. He saw oppression as a phenomenon of power in which relations between people and between groups is experienced in terms of domination and subordination, superiority and inferiority. At the centre of this phenomenon is control. Those with power control, those without power lack control (Charlton 1998, p.30). According to Charlton (1998) political, economic, and cultural contexts determine the similarities and differences in the experience of disabled people. He points out that the vast majority of disabled people have always been poor, powerless and degraded and that disability oppression is a product of both the past and the present (Charlton 1998, p.21).

1.3.2 Disability as Oppression in the Social Model

On the same theme Barnes and Mercer (2003) claim that powerlessness is a realisation of oppression, which confirms that disabled people have little control over, or choice in what to do with their lives. They point to the sharp divide between those who exercise authority or power (as in the case of professionals) and those who simply take orders and lack authority and status (Barnes and Mercer 2003, p.21). Their conceptualisation of disability is as a form of social oppression akin to sexism and racism although it exhibits a distinctive form, with its own dynamics. They claim that like sexism, and racism, 'disablism' expresses itself in exclusionary and oppressive practices at a wide range of levels: interpersonal, institutional, cultural and societal (Barnes and Mercer 2003, p.18). Lang (2000) notes that the social model is based on a concept from the industrialised West, embracing the notion of empowerment where rights are exercised

and decisions made in accordance with the preferences of an individual. He argues that in low resource countries the concept of individual rights as expressed in high resource countries is inappropriate and that decision making rooted in the ideology of individualism is often at variance with established cultural social norms and practices (Lang 2000). An example of this was provided by Momin (2003) who studied the integration of people with spinal cord injury in Bangladesh and reported that that decisions concerning an individual are often made in consultation with a family member on whom he or she depends and the prevailing approach is often shaped by religious beliefs.

Ahmad (2000, p.1) maintains that societal injustice is the root of disability and that a more inclusive environment would enable people with impairments to perform their role as citizens. He argues that although different cultural attitudes towards independence may modify how this model is perceived, the social model is both powerful and necessary as a model for conceptualising the discrimination experienced by people with impairments:

Some of the arguments about loss of control or independence in relation to the social model of disability may seem over-westernised to many for whom independence, mutual support and reciprocity are hallmarks of family and social relationships. Disabled individuals do still experience oppression and marginalisation, but their marginalisation can be understood only against what is considered 'normal' for someone of their gender age and class in their own cultures. Normalcy is not a given universal; thus impairments require to be seen in their social and cultural context (Ahmad 2000, p.2).

Priestley (2006), points out that an important distinction between the individual and the social model is provided by the emphasis in the discipline of disability studies. Disability studies utilising a social model approach might include studying oppressive social structures, environmental barriers and material or economic relationships of power. The emphasis here is on investigating the limitations of environments, and social structures, rather than individuals. Vasey (1992) qualified this further, stating:

The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design...it is a way of demonstrating that everyone, even someone who has no movement and sensory function and is going to die tomorrow, has the right to a certain standard of living and to be treated with respect (Vasey 1992, p.42).

This is an important point in relation to goals in education of workers in this field, the topic of chapter three.

Shakespeare notes that the experience of disabled people is dependent on the social context, and differs in different cultures and at different times. Rather than disability being inescapable, it becomes a product of social arrangements and can thus be reduced or possibly even eliminated (Shakespeare 2006, p.29). He also highlights the liberating impact of the model on disabled people themselves in that disabled people were able to understand that it was society that was at fault, not they themselves. This realisation has empowered them to mobilise for equal citizenship and demand equal rights.

1.3.3 Restoring a Social Relational Understanding of Disability

Thomas (2004) contends that the original social relational understanding of disability introduced in the writings of Finkelstein and Hunt in the 1970s has dissipated over time as its offspring, the social model of disability has gained popularity, and calls for this to be restored. She notes that the social model puts emphasis on social barriers that restrict the activities of people with impairments in the creation of disability. Bowe (1978) for example listed six barriers to the social inclusion of disabled people in 'Handicapping America' namely, architectural, attitudinal, educational, occupational, legal and personal or everyday problems. Thomas's (2004) contention is that the social barriers conceptualisation presents an oversimplified version of social relational thinking. She highlights the fact that that Finkelstein and Hunt had attempted to reflect theoretically on the nature of the social treatment in Britain in the 1970s and did so particularly in terms of welfarist reform. This included reflections on residential care, minimal benefits, exclusion from employment and educational mainstream and blocks on access to the built environment. The view put forward was that it was society's problematic response to people with impairment which produced disability and meant that political struggle should be directed towards changing society and enabling disabled people to gain control over their own lives. Importantly Thomas points out that the social model does not suggest that all restrictions of activity experienced by disabled people are caused by social barriers but equally it did not mean that living with the effects of impairment posed no difficulties for disabled people. What it did mean was that the difficulties related to impairment did not make up the substance of

disability. Her argument is that although impairment and illness do cause some restrictions of activity, in a social relational conceptualisation such non-socially engendered restrictions do not constitute disability.

Thomas' (2004) position on impairments and its effects as real but distinct from disability, is helpful for practitioners such as physiotherapists whose practical skills are often focused on reducing impairment and related physical effects such as pain and mobility limitation. Discussion of disability as distinct from impairment offers a helpful differentiation to promote thinking around intervention that may be needed. Impairment interventions are directed at the individual or family unit; disability interventions are social in nature and are directed at the wider society both materially and ideologically.

1.3.4 Criticisms of the Social Model

Since the late 1980s a number of other disability writers have been critical of the social model for overlooking oppressive aspects of impairment itself. French (1993), a physiotherapist, claimed that any attempt to uncouple impairment from disability contradicts an individual's everyday experiences on this basis. Barnes (1998) however argued that since impairment is an individual experience it could not be part of the social model itself. He insisted that this model is not however a denial of the importance of long term illness or impairment, appropriate medical or psychological intervention, or, indeed, discussions of these experiences (Barnes 1998, p.101). This is an important point of understanding for groups such as physiotherapists whose skill set usually addresses impairment and its effects and links to Oliver's (1990) defence of the social model; that it was intended to be a political intervention not a social theory. Another helpful explanation that highlights the value of the social model is given by Barnes (1991). In relation to the analytical division that the social model offers, removing the body/mind from the definition of disability makes it possible to identify the range, form and types of discrimination that make the world a difficult place for disabled people. Additionally the struggle for social inclusion does not constitute a rejection of the healthcare interventions that alleviate impairments. The distinct and separate analysis of society offered by the social model may also serve to highlight the lack of attention paid to this topic by groups such as Allied Health Professionals whose focus is traditionally on deficit problems at an individual level.

Hurst and Albert (2006, p.27) address the issue raised by critics of the social model that it ignores the reality of what impairment means for disabled people. It is claimed that whereas as an issue, this is problematic in the North but when applied to the South it is catastrophic. Hurst and Albert's counter argument is that advocating the social model does not mean ignoring the causes of impairment or the healthcare needs of anyone, including disabled people. They claim that the social model critique of the medical model is about rejecting the medicalisation of disabled people, not rejecting medical intervention. They answer a specific related criticism raised by Werner (1998, p.6) who claimed that disability activists in the North have prioritised the struggle for social rights, partly because they already have the essential assistive technology they require. By doing this, claimed Werner, they have tended to project their own priorities onto the poor disabled people of poorly resourced countries. For people in these situations, however, lack of assistive equipment may be their biggest limitation. In response, Hurst and Albert (2006, p.27) assert that access to personal aids such as a wheelchair or a hearing aid is a basic human right for someone who would otherwise be unable to take part in a social activity. In their view, practices prioritising the real needs of disabled people given their participation are not antithetical to a human rights approach to disability. Furthermore, some of the most vocal proponents of disability rights have been from the South. A further objection has been raised regarding the cultural relativity of the social model, which emerged in a cultural context with an emphasis on individual rights. This differs from the more family-based or communal situation found in many developing countries, where, it is claimed, some practices might be defended on the grounds that they are part of the local culture. Hurst and Albert (2006, p.26) stress the continued need for a cultural adaptation of the social model by disabled people in these contexts, and claim that this is precisely what has happened already in many developing countries.

These debates around the social model have clarified its intention and distinctiveness. Whilst not undermining the importance of impairment, it firmly separates disability causally from impairment and locates it within society.

'It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organisation' (Oliver 1996, p.32).

Shakespeare and Watson (2001) have suggested that a model which was developed in the early 1970s no longer seems useful at the beginning of the twenty-first century and that it is time for another paradigm shift towards a model which will account for disabled people's experience more effectively. This seems a somewhat premature call given the tardiness of groups such as Allied Health Professionals to examine its possible use. Only in July 2009 were calls made for the promotion of an awareness and understanding of the social model of disability and closer engagement with disabled people's organisations in the Chartered Society of Physiotherapy's International Policy and Strategy Statement (CSP 2009). These calls came from CSP's international advisor and were linked to the promotion of patient care and workforce practices based on ethical, environmentally responsible, rights-based principles (CSP 2009). It was prompted by an acknowledgement of the reticence of the UK physiotherapy professional body to engage with international discourse on disability. The fact that these calls are emerging over thirty years after the social model of disability was conceptualised is indicative of the entrenchment of physiotherapy as a profession in medical discourse. Few physiotherapy educators in the UK have engaged with the discipline of disability studies and exposure to the social model of disability in physiotherapy education is minimal. In the author's experience, Bangladeshi physiotherapy students regard Western professional practice as benchmarking excellence. It is hardly surprising therefore, that Bangladeshi engagement in dialogue and critical analysis of assumptions underpinning traditional practices in physiotherapy, has yet to occur. This is discussed further in chapter three.

1.3.5 Transference of Ideas from North to South

According to Priestley (2006, p.25) the social model approach has emerged from the political activism of disabled people, based on their experiences of discrimination and oppression. Disability studies have become a vibrant and distinct international discipline but the literature has been dominated by contributions from authors in rich countries and material written in English. Although Priestley (2006, p.24) points out that much of this work has great potential for thinking about disability in the South too, he notes that it is important to retain some caution about the ease or desirability of transferring Northern solutions to Southern problems. Wirz and Hartley (1999) have previously highlighted similar issues.

1.3.6 Summary

The social model of disability was fuelled by the lived experiences of disabled people and represents a social interpretation of disability relocating both the problem and the need for change from the individual to the society. In socio-political terms disability is interpreted as the outcome of an oppressive relationship between people with impairments and the rest of society. In this model a clear distinction is made between impairment and disability. The social model has the potential to become a powerful political tool to fight discriminatory practices. Physiotherapy as a profession has been slow to acknowledge this model. Critics of the social model have focused on its failure to recognise the role of impairment and the inability of the model to encompass the range of different impairment/disability experiences. However this distinction has been stoutly defended by proponents of this model in terms of the differentiation this model allows between disabling responses to impairment and the impairment itself.

1.4 Section Four

1.4.1 Disability as an Interaction of Individual and Structural Factors

The level of debate around the nature of disability highlights the importance given to the topic. Its relevance to this research relates to the ways in which training and education equip people to think about and respond to the needs of disabled people and this is clearly an ongoing dynamic. Various authors have changed their positions on the definitions they now argue for. Shakespeare and Watson (2001) for example now reject the conceptual separation of impairment from disability in the social model. They see this reduction of impairment to the biological as problematic, arguing that impairment is profoundly social because the words used and the discourses deployed to represent it are socially and culturally determined. Shakespeare presently maintains that disability is always an interaction between individual and structural factors claiming that 'people are disabled by society and by their bodies' (Shakespeare 2006, p.56). He now supports a definition of disability as the outcome of the interaction between individual and contextual factors. These include impairment, personality, individual attitudes, environment, policy and culture (Shakespeare 2006, p.58). He argues that the binary distinctions of social/medical models and impairment/disability definitions are primary and secondary dichotomies (Shakespeare 2006, p.10). With the exception of Priestley's (1998) fourfold typology, he proposes

that British disability studies have relied on these binary distinctions and they are misleading and dangerous (Shakespeare 2006, p.10).

Several other authors have expressed difficulty sustaining the impairment/disability distinction. Wall (1999) approached the issue from the standpoint of the experience of pain. He identified that pain is generated through the interplay of physiological, psychological and socio-cultural factors and thus the individual experience can never be separated from the social context. Abberley (1987) pointed out that impairments are often caused by social arrangements. In his qualitative study with people who experience acquired brain injury, Sherry (2002) concluded that the impairment and disability experiences were best conceptualised as a fluid continuum not a polar dichotomy. Williams (1999) appealed for an approach that gives weight to different causal levels in a complex disability experience. In his view:

Disability is an emergent property, located, temporarily speaking, in terms of the interplay between the biological reality of physiological impairment, structural conditioning (i.e. enablements/constraints) and socio-cultural interaction/elaboration (Williams 1999, p.810).

Danermark and Gellerstedt (2004, p.350) have also argued for an interaction of mechanisms. They suggest that injustices to disabled people require an understanding that these are not generated by solely cultural mechanisms nor by socio-economic mechanisms, nor by biological mechanisms. Shakespeare (2006) notes that a social contextual approach to disability has been an aspect of Nordic Research also: The 1967 Norwegian White paper on disability stated 'rather than expecting that disabled people one-sidedly shall adapt to the society we also need to adapt the environment to them' (Stortingsmelding 88, 1966-67). The understanding in the Nordic approach is that disability is a mismatch between the individual and the environment and that it is situational and relative (Tøssebro and Kittelsaa 2004).

The idea of disability as an interaction is also contained in the preamble of the UN Convention on the Rights of Persons with Disability. This states:

'Disability is an evolving concept, and.... results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder full and effective participation in society on an equal basis with others' (United Nations Enable 2008).

This interactive model is distinguished from the social model of disability in that it recognises the environment as a problem but not the problem of disability. Thus, unlike the conceptualisation of the social model the definition disability becomes a relative concept which varies according to the context and environment. In this conceptualisation, disability is a condition which can be modified by reducing an impairment or by developing abilities at an individual level or by attending to the environment. This idea has been retained in International Classification of Functioning Disability and Health (ICF) proposed by WHO in 1999.

1.4.2 International Definitions of Impairment and Disability

WHO's first International Classification of Impairments, Disabilities, and Handicaps (ICIDH-1) was published in 1980. This suggested conceptual distinctions among three levels of performance—impairment at a bodily structural level, disability at the person level, and handicap at a societal level. Impairment was defined in biomedical terms as any loss or abnormality of psychological or anatomical structure (WHO 1980, p.29). This judgement was based on deviations from accepted ranges of normal physiological functioning. There was in this classification a suggested causal link between impairment and its consequences, referred to as 'disablement' and the classification focused on measurable difference and 'otherness'. Criticisms of the classification system resulted finally in the publication of a revised version in 1999, the International Classification of Functioning, Disability and Health, ICIDH-2, commonly known as ICF (WHO 1999).

WHO (2001) describes ICF as a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Acknowledging that an individual's functioning and disability occurs in a specific context, a list of environmental factors is also included. This allows for a record of the impact of the environment on the person's functioning. ICF claims to take into account the social aspects of disability and claims not to see disability only as a 'medical' or 'biological' dysfunction. WHO (2001) states: 'By including contextual factors, in which environmental factors are listed, ICF allows a record of the impact of the environment on the person's functioning'. According to WHO (2001, p.28) ICF uses a bio-psychosocial approach in an attempt to achieve a synthesis in order to provide a

coherent view of different perspectives of health from a biological, individual and social perspective.

Within ICF impairment retains the original definition used in ICIDH-1 of a loss, abnormality or defect in body structure or physiological function and includes mental functions. Abnormality here is used strictly to refer to significant variation from established statistical norms. Disability becomes an umbrella term for impairments, activity limitations and participation restrictions. It denotes negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (WHO 2001, p.190). The components of ICF are shown in fig 1.1 below.

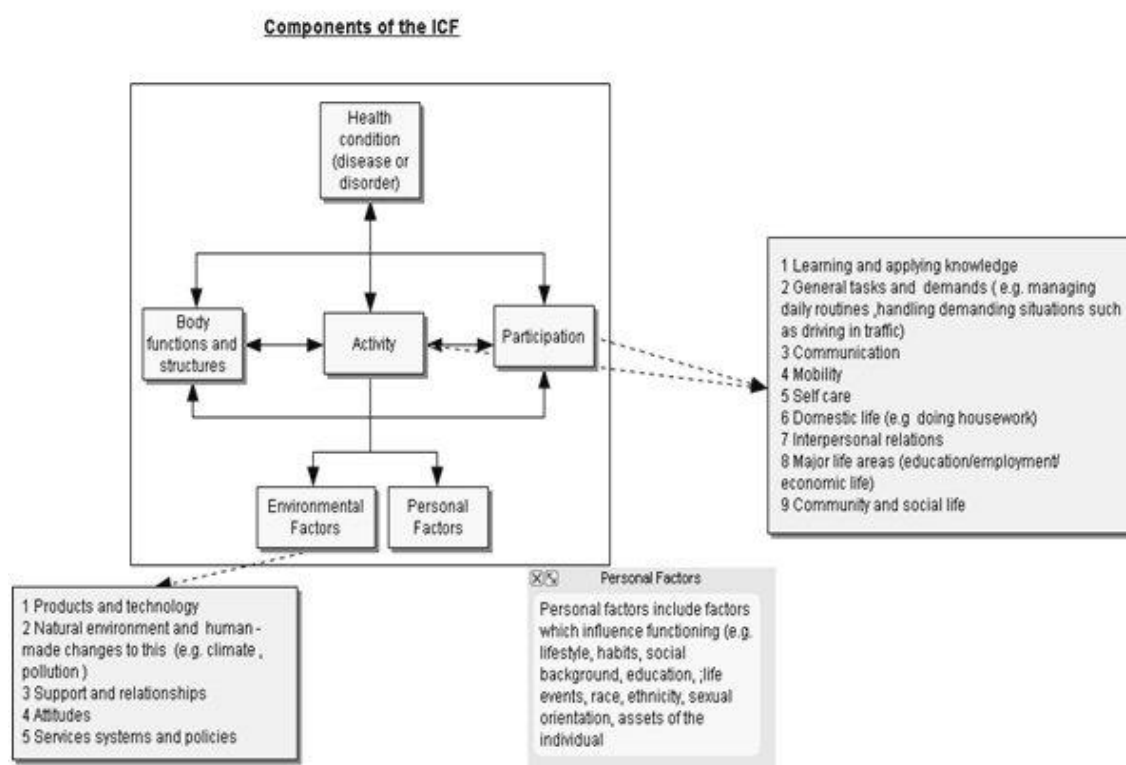


Figure 1.1 : International Classification of Functioning, Disability and Health (ICF)

1.4.3 Responses to the Revised ICIDH-1 Classification(ICF)

Criticisms of the revised classification quickly ensued from several authors (Finkelstein 1998; Baylies 2002; Barnes and Mercer 2003; Hurst 2000). These centred around the continued emphasis on impairment and the strong individual focus maintained in the revision, despite the assertion from Disabled Peoples International and Union of Physically Impaired against Segregation (UPIAS 1976), that disability, as distinct from

impairment, has social causes rather than biological. Hurst (2000) argued that although the revision opened up new possibilities for socio-medical analysis of disablement it retained individualistic medical notions of disability as the cause. His conclusion was that the revised classification, ICDH-2, had retained the same ideology as the ICHDH-1 and remained a 'Classification of Health' (Hurst 2000, p.1085). Siyabulela and Duncan (2006, p.301) asserted that the classification itself ran the risk of becoming another disabling barrier as it reduced the experience of disabled persons to descriptions of impaired body functions activities and participation.

A further point was raised by Hurst (2000). He questioned the need for in-depth classification of individual differences as a prerequisite for provision of services or implementation of policies to assure their rights. In relation to this point it is instructive to note that the Spinal Injuries Association in Britain has successfully planned programmes and delivered services by asking people directly about their needs without recourse to a system to classify the consequences of injury.

A further concern relates to the extensiveness of the classification system and its usefulness as a tool in developing contexts. ICF offers several hundred alternative coding categories. Adopting this in the developed world requires specific training e.g. detailed guidance on using ICF was published by The College of Occupational Therapists (COT) in the UK (COT 2004). In countries such as Bangladesh the scarcity of therapeutic services means that if disabled person sees a rehabilitation worker at all it is likely that their training would have been of a few months duration only. The feasibility of including adequate ICF training in rehabilitation worker preparation is questionable and points to the need for a simpler system which will quickly establish priorities for action.

More fundamental criticisms of ICF have been raised around the activity of classifying human differences. The purpose of ICF is to classify deviations from assumed norms in every area of life. In doing so ICF fosters a negative view of disabled people coding deficits from an assumed normal rather than identifying them as people with ability and resources (Whalley Hammell 2006, p.18). Bickenbach (1993) claims that disabled people are represented in this taxonomy as defective, deviant, subnormal and inferior. Disability theorists claim that both ICDH and ICF facilitate the type of thinking that leads to eugenics (Pfeiffer 1998).

In the ICF the environment is depicted as impacting the individual but specifically not the disease or disorder. Baylies (2002) also commented on the absence in ICF of an equivalent capacity for classifying and coding the discriminatory dimensions of societies, the performance of governments or the effects of their policies. She pointed out that the policy makers' actions do not undergo any scrutiny at all within ICF, and it is their actions that have power to create changes and their failure to act that maintains the status quo.

This is an important consideration where there is a failure to enact policy or laws. Rahman (2006) for example identified and analysed the failure of the government in Bangladesh to actualise policy on disability. ICF however has no way of identifying the ramifications of this failure, nor for contemplating the role of environments e.g. unsafe work environments in the creation of impairments.

Hammell (1998) suggests that systems of classification act as tools to assist professionals and bureaucrats in their work but do not have any inherent benefit for those being coded and classified. It is important to note that this classification of disability (as an interaction between individual and societal features) contained in the ICF has been accepted by World Confederation of Physical Therapists (WCPT) who are actively promoting this model in collaboration with WHO. This is discussed further in chapter three.

1.4.4 Impairment as a Non-permanent Feature

Definitions of impairment used in ICF imply the idea of a relative permanence. This idea is implied in other definitions that have been used in the past including that used by the Union of Physically Impaired against Segregation (UPIAS). UPIAS was one of a number of disabled peoples' organisations that emerged in the 1970s. UPIAS defined impairment as 'lacking all or part of a limb, or having a defective limb, organism or mechanism of the body..' (UPIAS 1976, p.3). Shakespeare (2006) however pointed out that impairment may not remain constant in a person's life. Blaxter (1976) has suggested that impairment should be seen as a continuum rather than a polar opposite to normality. This idea would incorporate impairments commonly encountered that do not significantly impact a person's function and may only be temporary.

Sutherland (1981) contested the idea of 'otherness' contained in the definition of impairment in ICIDH-1 by contending that impairment is a universal phenomenon and in that sense every human being has limitations and vulnerabilities and ultimately is mortal. This links well with the observation that impairments in older people are commonly accepted as a part of the ageing process and indeed it is their marked absence in an older person that draws attention to their 'otherness'.

In relation to the developing contexts, Miles (2001) pointed out that approaching impairment in biomedical and individualistic terms is peculiar to Western philosophical and cultural traditions. Despite this, minority world perspectives have been strongly promoted and have gained acceptance in international forums. A balanced view therefore requires that perspectives of the majority world are researched, presented and acted upon. The interest of this research inquiry is the application of this knowledge to inform the knowledge base of practitioners working in the field of disability in the context of Bangladesh.

1.4.5 Summary

The primary use of ICF classification proposed by WHO is thus for collection of statistics, research and determining eligibility for services. ICF attempts to combine individual and social models of disability. It has been criticised by several authors as a framework which categorises disabled people as defective and maintains a strong causal link between impairment and disability. Training required in the effective use of this tool in poorly resourced contexts presents a barrier to its implementation. Ideas of the relative permanence of impairment and the idea of 'otherness' linked with definitions of impairment in ICF have been questioned. Although biomedical and individualistic approaches to impairment are peculiar to Western philosophy and cultural traditions they have gained acceptance in international forums. Majority world perspectives on disability remain a fruitful area of enquiry.

1.5 Section Five

1.5.1 A Taxonomy of Disability : Fourfold Typology of Disability

In view of the above debates around definition Priestley proposed a versatile fourfold typology of disability (Priestley 1998). He identified that the individual model focused on either biological or psychological explanations of disability (negotiated aspects of

individual identity and adjustment) and the social model clustered around two types of explanations namely structural accounts (identifying causative political economies and disabling environments) and cultural accounts of values and representations. He suggested that distinguishing between these approaches using four headings may be helpful. A simplified form of this typology is shown in table 1.1 below.

Table 1.1: Four approaches to disability (adapted from Priestley 1998)

	Materialist explanations	Idealist explanations
Individual models	Biology	Psychology
Social models	Structure	Culture

This typology importantly allows considerable room for overlap between the four basic categorisations of disability allowing the complex nature of disability to be explored from one or more of these aspects. Indeed Priestley (2003) suggests that it might be more appropriate to view the four theoretical approaches as overlapping areas rather than as discrete conceptual boxes fitting neatly into either individual or social models of disability. Figure 1.2 provides a more useful framework for thinking about disability and its various representations in social science. Looking at disability in this way allows the complexity of disability to become more apparent (Priestley 2003, p.17)

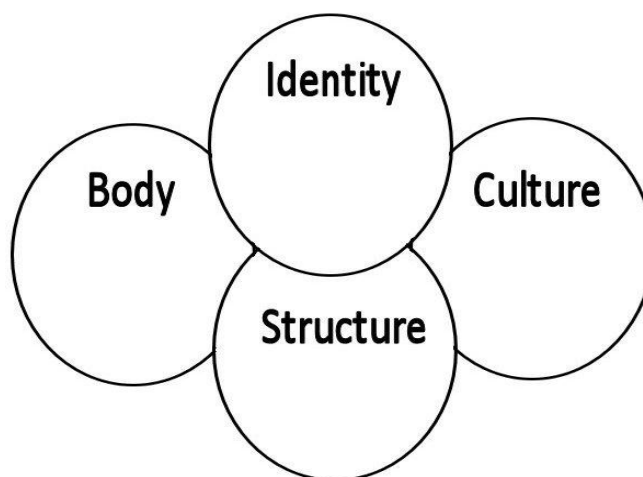


Figure 1.2: The Complexity of Disability (Taken from Priestley 2003, p.17)

As perception of the problem influences the responses considered appropriate, typology is very important. This model offers a solution to the inadequacy that appears by adopting a polarised position in any one of the fields. Priestley notes:

...it would be quite wrong to consider all approaches to disability based on the body or impairment as simply biological in their orientation... Biology is relevant

to understanding the body, but environments and social processes play a big part too (Priestley 2003, p.16).

This principle of the overlapping of these basic types can be applied equally to the identities of disabled people. Priestley explains this in the following way:

The personal life experiences of disabled people are not simply the product of individual cognitive psychology but are deeply embedded in the social. Individual identities are negotiated with others in a social context, in response to cultural values and structural forces (Priestley 2003, p.16).

An important aspect of this typology is that it differentiates not only between materialist and idealist constructions of disability but also between individual and social model constructions. 'Idealist' refers to a construction of phenomena (in this case disability) that assumes the generative cause to be in the realm of culture and ideas, rather than material causes such as economy, environment or relations of power. The assumption adopted by a social idealist position is that it would be possible to eliminate disability, in the social model sense, by changing culture and attitudes rather than needing to change the material relations of power.

Priestley acknowledges that though keeping all these factors in view at the same time represents a 'significant intellectual challenge' this 'framework of multiple approaches' offers the potential for a more comprehensive account of disability than could be gained by remaining within a single paradigm of enquiry (Priestley 2003, p.18). The taxonomy appears to be relatively straightforward to apply to a specific situation by examining the four explanations individually and considering areas of overlap. It allows any one aspect of disability to be examined in greater detail whilst not detracting from the value of simultaneously holding a bigger picture of a more complex whole. It allows for contextual differences and can be applied in widely varying situations exhibited in both minority and majority world contexts. This versatility is a useful feature in a study seeking to examine ways in which disability is experienced and responded to e.g. in discussions around the value of interventions underpinned solely by an individual model of disability, or when discussing religious beliefs around disability. Where the discussion relates to wider social processes around disability the typology accommodates an examination of their impact in offering a structural explanation of disability. It is similar to a framework of analysis suggested by Thompson (1997, p.20) who advocates the analysis of inequalities and discrimination

at three levels (P, C and S) namely personal or psychological, cultural and structural, which are interlinked and constantly interact with each other. The usefulness of a 'PCS analysis' is therefore discussed further in chapter two which explores context in greater detail.

1.5.2 Approaches to Disability Adopted in this Thesis

The thesis concerns the education of physiotherapists and related healthcare personnel around disability in Bangladesh. With reference to the above discussions on definitions of impairment and disability it is important to clarify the interpretation and implied meaning of terms used in this thesis. Finkelstein (1993, p.10) has suggested that there is a general confusion around use of the term disability. This confusion surrounds its common usage, both in spoken and written forms, as a synonym for physical impairment with accompanying negative associations. Those who have accepted and adopted a social model definition of the word disability use it only to refer to people with impairments who suffer discrimination. I have adopted this application throughout the thesis with the added qualification of the term, as follows:

The use of the term 'disability' in this thesis implies a social relational understanding of disability as proposed by Thomas (2004) i.e. 'Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Thomas 2004). In this thesis I use the expression 'disabled people' as opposed to 'people with disability' in keeping with this position.

The term 'impairment' is also used in a deliberate way. I use impairment to refer to a bio-physiological limitation. 'Impairment effects' are the consequences of impairment e.g. pain, or mobility limitation. Impairment and /or its effects are understood to be experienced on an individual basis. The presence of impairment, however, does not mean automatic transfer to the status of a disabled person.

Personnel working in the field of disability in Bangladesh are often focused in their work on impairment and impairment effects. This is regularly done in situations where discrimination and exclusion of such individuals is a prominent feature. It has been noted that the lives of disabled individuals around the globe are usually far more limited by prevailing social, cultural and economic restraints than by physical, sensory,

psychological or intellectual impairments (Groce 1999a). Applying the definitions above will enable discussions relating to both disability and impairment and its effects to remain distinct. This distinction is an important concern of this study, as one of the main goals of the thesis is to positively impact the preparation of individuals to meet the needs of disabled people. This distinction also allows me to refer to terms used in International Classification of Functioning, Disability and Health (ICF) known also as ICDH-2 (WHO 1999) (See fig. 1.1). This categorises impairment and activity limitations and participation separately and acknowledges that all of these may be affected by environmental or personal factors.

It is important also to note that when sourced literature has used the term disability less specifically or with a different definitional understanding, e.g. has used the term 'people with disability' where I would have used 'disabled people', these sources are quoted in their original text and are to be understood in keeping with the meaning and the spirit implied in their use by their respective authors.

1.5.3 Summary

A fourfold typology of disability was suggested by Priestley (1998) and its features explored. It provides an overview of explanation of disability which is versatile and of relevance when seeking to understand the complex nature of disability.

1.5.4 Chapter One Conclusion

This chapter began by identifying the definition of disability in the Disability Welfare Act of 2001. Vocabulary used in the legislation reflected perceptions around disabled people by the Government of Bangladesh at the time of this research. New ways of thinking and writing about disability have emerged mainly in different parts of the minority or developed world in the last four decades, mainly drawing on the perspectives of disabled people. These writings and the ideas they have conveyed around disability are explored in this chapter. One of their key features has been the introduction and development of various models of disability. The examination of three prominent models has been the main content of the chapter. These are the individual, social models of disability and the more recent proposal of disability as an interaction of individual and structural factors. The International Classification of Disability Functioning and Health (ICF) developed by WHO and supported by WCPT has

also been identified and discussed. A fourfold taxonomy suggested by Priestley (1998) encompassing the various explanations of disability has been examined. This is similar to a PCS analytical framework which considers inequality and discrimination at three levels i.e. personal or psychological, cultural and structural. These will be utilised further in relating the data analysis to existing theory. The second chapter will explore the experience of disability in relation to contexts.

Chapter Two

2. DISABILITY AND CONTEXT

2.0 Introduction

The purpose of the second chapter is to examine disability in greater detail in relation to socio-cultural considerations, and to identify issues of relevance to the education of workers in this field.

The importance of this topic to all healthcare practice is being increasingly recognised. Crisp (2010), for example now maintains that healthcare practitioners should become more aware of the primacy of a 'social diagnosis.' This implies that understanding and working with respect to the social situation of the patients should take precedence over making a clinical diagnosis of illness or disease. In relation to occupational therapy, Kronenberg et al (2003) propose re-thinking traditional occupational therapy roles, and Thibeault (2005, p.240) states 'Maybe the time has come to define our role more explicitly as agents for social change'. In relation to healthcare professional education, Twible and Henley (2001, p.158) write 'Education about culture and community needs to be embedded across all the curricula and permeate all aspects of the educational process.' Richardson (2001, p.44) also stresses the importance of professional craft knowledge which is, 'drawn from the experiential knowledge of how to go about healthcare *within particular contexts*' (author's emphasis). Social context is therefore an important consideration.

It was noted in chapter one that within a social model perspective, disability is located in society, 'disability is wholly and exclusively social' (Oliver 1996, p.34). Also, explanations of disability include both materialist and idealist analyses which are inter-related rather than separate debates (Priestley 1998). Materialist analyses stress the primacy of the economy and environment in shaping culture and focus on structural and institutional barriers, whilst idealist analyses emphasise the social construction of disability in cultural terms and focus on disabling attitudes and representations. Chapter 2 discusses disability in majority world contexts in relation to these analyses, with reference to Bangladesh as an example.

This chapter is divided into five sections. Section one begins with a theoretical underpinning of disability as a form of social oppression linking this with discrimination and the denial of rights and suggests how these processes may operate in society. Section two looks at the role of material factors in the creation of disability with particular reference to developing contexts. Sections three and four are concerned with idealist analyses of disability. Section three examines identity negotiation and factors influencing this, in particular the use of language around disability in Bangladesh. Section four looks at the way in which responses to impairment are often based on a mix of cultural and religious beliefs, examining Islam and Hinduism as the dominant religions in Bangladesh. Section five looks at family and kinship systems in Bangladesh and considers how individualist and collective value systems might impact behaviours (both user and student) in relation to this research. Finally, a chapter conclusion is drawn.

2.1 Section One

2.1.1 Understanding Disability as Oppression

Finkelstein (1980, p.47) argued that disability is 'the outcome of an oppressive relationship between people with impairments and the rest of the society.' According to Thompson (2003) oppression is a result of negative discrimination and is closely linked to it. He writes, 'Negative discrimination involves not only identifying differences but making a negative attribution to these, i.e. attaching a negative or detrimental label or connotation to the person, group or entity involved' (Thompson 2003, p.10). Thompson suggests that the fundamental source of oppression is the set of processes by which certain social groups are discriminated against and therefore disadvantaged. Alongside major social divisions in society such as class, ethnicity, gender and age, disability has also been identified as a concept which distinguishes a certain proportion of the population (those with a degree of physical impairment) from the 'able-bodied majority' (Oliver 1983, 1996). The systematic discrimination and prejudice against disabled people as a social division which produces a milieu of oppression and degradation, is known as 'disablism' (Thompson 1997, p.106).

Thompson links oppression closely with the denial of the rights of individuals and groups by more powerful groups and defines oppression in the following way:

'Inhuman or degrading treatment of individuals or groups; hardship and injustice brought about by the dominance of one group over another; the negative and demeaning exercise of power. Oppression often involves disregarding the rights of an individual or group and is thus a denial of citizenship.' (Thompson 2001, p.34).

Rights can be divided into three sets, namely civil, political and social rights (Marshall 1963). Empowerment contributes to the process of challenging oppression (Ward and Mullender 1993) and includes the assertion of rights. Mishra (1981, p.27) described social rights as comprising of 'a modicum of economic welfare and security' and the 'right to share to the full in the social heritage and life of a civilised being according to the standards prevailing in the society'. The term 'standards prevailing in the society' suggests that social rights are not absolute and need to be understood in the context of the society concerned, (Thompson 2003, p.8). Thompson also suggested that in any social context, discrimination leading to oppression can be seen to operate at three distinct but inter-related levels: personal or psychological, cultural and structural (Thompson 2003).

The interplay of these levels is illustrated in Fig. 2.1 below. Included at an individual or personal level (P) are thoughts, feelings and actions. P also refers to practice, individual workers interacting with individual 'clients' and to prejudice which Thompson (2003) describes as the inflexibility of mind which stands in the way of fair and non-judgemental practice. C refers to cultural levels of shared ways of seeing, thinking, and doing. It relates to commonalities – values and patterns of thought and behaviour, an assumed consensus about what is right and what is normal. It produces conformity to social norms. Culture is therefore an important consideration when examining attitudes to disabled people, and will be explored in greater depth later in this chapter. People are, however, also categorised according to social divisions such as class and gender. These divisions form the basis of the social structure i.e. the network of social relationships, institutions and grouping. These divisions play an important role in the distribution of power, status and opportunities (Thompson 1997, p.15). 'Structure' relates to the ways in which oppression and discrimination are institutionalised and thus 'sewn in to the fabric of society'. It denotes the wider level of social forces and the socio-political dimension of interlocking patterns of power and influence, (Thompson 1997, p.20). Thus disablism can be seen to operate at all three levels.

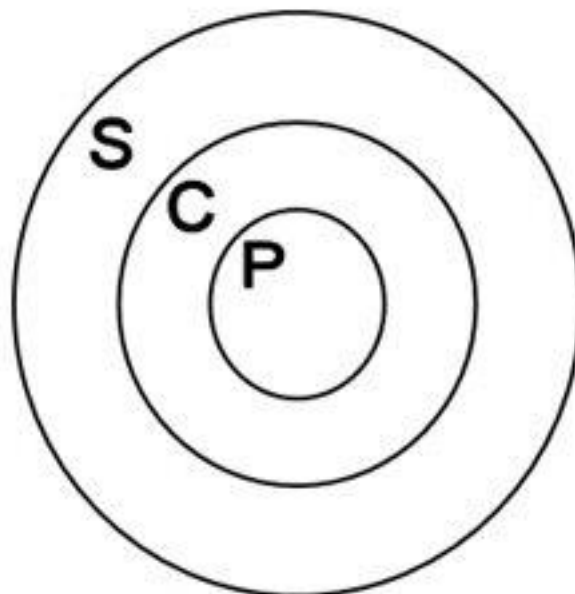


Figure 2.1 : The interplay of personal, cultural and structural levels in society.

(Taken from Thompson 1997, p.21)

Thompson (2003, p.14) points out that all individuals operate within a cultural context where beliefs, values and actions owe a great deal to prevailing norms and expectations. Although at a personal level discrimination operates as prejudice, the personal (P) is thus embedded in the cultural (C).

Understanding the social location of disabled people in any context requires an examination of both structure and culture and the way these interact. Thompson's (2003) analysis of structure involves the examination of social, political and economic aspects of social order. Social factors include issues relating to social divisions. Political factors include distribution of power both formally and informally (including power relations between individuals, groups etc.). Economic factors include the distribution of wealth and other material resources, (Thompson 2003, p.16).

According to Thompson (1997, p.24) oppression is often built into structural and institutional patterns and organisational policies. Discrimination acts as a reflection and reinforcement of these structured inequalities. Inequality can be seen to involve an undermining or denial of rights (Thompson 2003). A knowledge of the rights of disabled people as a group is necessary in order to understanding their experience of disablism.

2.1.2 The Rights of Disabled People in Bangladesh

The National Constitution of Bangladesh (1972) was formulated after the War of Independence with Pakistan and includes a description of the rights of all its citizens. It is noteworthy that disabled people are equally entitled to all the rights, entitlements and fundamental freedoms enshrined for all citizens of the country, and to those rights contained in treaties on human rights that the government becomes a party to. The Constitution states:

'It shall be a fundamental aim of the State to realise through the democratic process...a society in which the rule of law, fundamental human rights and freedom, equality and justice, political, economic and social, will be secured for all its citizens'.

This includes the provision of basic necessities:

'It shall be a fundamental responsibility of the State to attain, through planned economic growth, a constant increase of productive forces and a steady improvement in the material and cultural standard of living of the people, with a view to securing to its citizens (a) the provision of the basic necessities of life, including food, clothing, shelter, education and medical care; b) the right to work, that is the right to guaranteed employment at a reasonable wage having regard to the quantity and quality of work; (c) the right to reasonable rest, recreation and leisure; and the right to social security, that is to say to public assistance in cases of undeserved want arising from unemployment, illness or disablement, or suffered by widows or orphans or in old age, or in other such cases (International Relations and Security Network, n. d.).'

The specific rights of disabled people at the time of data collection had been secured in the Disability Welfare Act enacted in 2001. This legislation was discussed previously (Chapter 1, Section 1.1.2). In 2008 Bangladesh ratified the Convention of the Rights of Persons with Disability. Thus two major pieces of legislation now secure the specific rights of disabled people in Bangladesh in addition to those contained in the National Constitution of Bangladesh (1972). Commenting on the realities of the situation in 2009, the Disability Rights Watch Group in Bangladesh reported the following: 'International instruments concerning rights of persons with disabilities have been signed by the Government of Bangladesh, but most are still not being implemented'. Accordingly to this group, the denial of rights, privileges, entitlements and fundamental freedoms to disabled people would continue 'until and unless disability is addressed and accepted as a cross-cutting development and rights-based agenda by all' (Disability Rights Watch Group 2009).

The Watch Group report pointed out the differences and inconsistencies in major areas between the two pieces of legislation, partly underpinned by the different ways in which disability was conceived. In the first legislation disability was seen as a welfare and charity issue, in the second as a development and rights-based issue.

It would be naïve to assume that the signing of international treaties around disability would automatically ensure a change of perspective or practices maintaining inequality within a nation. Establishing rights does not change attitudes embedded deeply within a culture. According to Maloney, (1991, p.40) inequality in interpersonal relationships is seen as normal: 'the principle of hierarchy in interpersonal relationships is accepted as morally right and necessary as in South Asia generally, and is ritualised in many ways'. His observations highlight the importance of culture in relation to lived experience of poverty and disability. Maloney (1991) maintains that Bangladesh is one of the most difficult countries in the world in which to promote projects aimed at development goals. He argues that cultural factors (such as the patterns of strongly hierarchical behaviour exhibited) have a major impact on poverty and prosperity in the society as a whole. Rahman (2006) also implicates cultural practices as a major barrier to actualising change in Bangladesh. He claims that bribery is widely practised and is on the increase due to the dominant mass conviction that even the simplest thing will not move automatically. Actualising the rights of disabled people within such a context presents a formidable challenge.

Thompson (2003) links the achievement of social rights with the provision of effective human services. He links the notion of 'sharing to the full in the social heritage' with marginalisation and associates this with inequality where socially disadvantaged groups are 'pushed to the margins of mainstream society' (Thompson 2003, p.8). In Thompson's view, marginalisation is a key element in the development and maintenance of inequality.

In Bangladesh disability services in rural areas are mainly run by NGOs and have a strong Western influence. Writing about the context of Jordan, Turmasani (1999) implicates Western influence per se in the marginalisation of disabled people. He is critical of the view that equates 'institutes' and 'special' with 'disability provision' (as introduced by international NGOs and agencies) and claims that this promotes exclusion from 'mainstream' services and discourages the provision of state-run and

state-funded services. An alternative perspective is offered from Bangladesh by Khandaker (2011) who maintains that waiting for the State to take the initiative to provide necessary services means the wait will continue indefinitely. Rahman (2009) claims that Bangladeshis possess a low and declining degree of trust in their political institutions and political leaders and Khandaker's statement supports this.

2.1.3 Summary

Oppression can be examined in terms of the social processes producing it. Disability as a form of social oppression can be linked with discrimination. The denial of rights and the processes which produce this may operate at three levels in society. Disability as an oppression is linked to the denial of rights. Initial reasons suggested for denial of the rights of disabled people in Bangladesh have identified a failure of government to enact rights which are protected in adopted legislation. However behavioural causes have also been implicated in the perpetuation of marginalisation impacting the lives of disabled people. Links between poverty and disability are further examined in the next section.

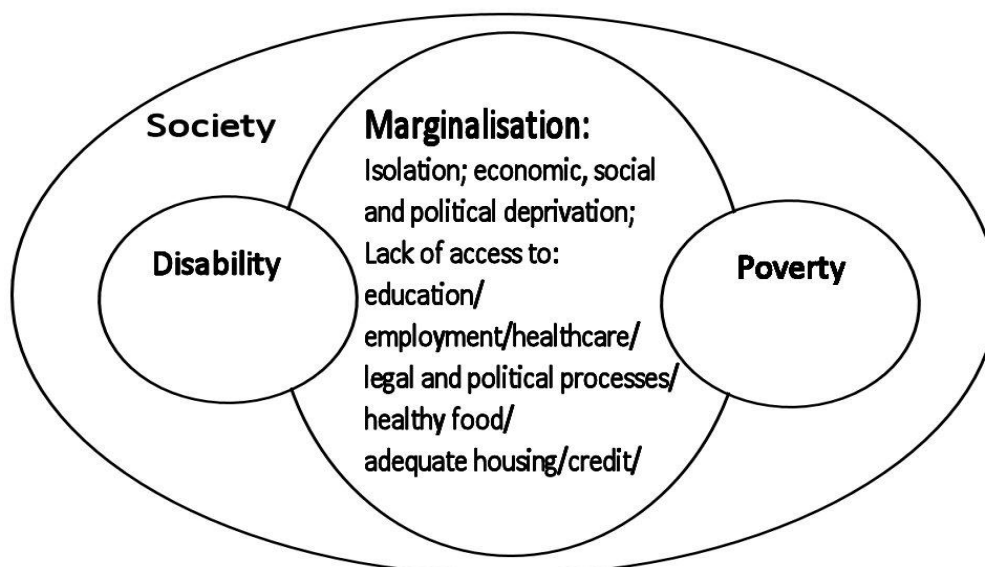
2.2 Section Two

2.2.1 The Role of Material Factors in the Creation of Disability

Materialist analyses of disability stress the primacy of the economy and environment in shaping culture, and in these terms focus on structural and institutional barriers (Priestley 1998). In the last decade the relationship between poverty and disability has been strongly established (Emmet 2006), with most of the major international development agencies now placing disability on their development agendas. The United Kingdom's Department for International Development (DFID) declared that 'Eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account' (DFID 2000, p.1). Based on the estimation that 400 million disabled people in developing countries are surviving on less than \$1 a day it is highly unlikely that the Millennium Development Goals can be achieved if the relationship between poverty and disability is not addressed and understood better (DFID 2011). The awareness that disability as a cross-cutting issue is under-researched has led to its emergence as a current research topic. In 2009 DFID instituted a research programme which aims to provide evidence on how disability

interacts with other factors influencing poverty. It is significant that the research programme seeks to explore how the uptake of knowledge on disability can be improved, by developing country policy-makers and international organisations. This not only points to the question of raising awareness about disability and its link with poverty, but also to the importance now given to linking the two together, i.e. seeing disability as a development issue.

Priestley maintains that it is important to recognise that disability, considered as a social phenomenon, is about discrimination and exclusion (Priestley 1998, p.85). Put in another way 'from the socio-materialist position disability can be regarded as the material relations of power arising from the development of political economy and/or patriarchy within a specific historical context' (Priestley 1998, p.80). Dube and Charowa (2005) argue that poverty is a symptom of imbedded structural imbalances and results from limited or no access to basic infrastructure and services and other resources needed to ensure sustainable livelihoods. Yeo (2006) maintains that all the features of poverty equally relate to disabled people and suggests that the relationship between poverty, disability and marginalisation can be represented by an interlocking circle shown in Fig 2.2 below:



**Figure 2.2 : Relationship between poverty, disability and societal features.
From Yeo (2006)**

The World Bank estimates that 20% of the poorest people in the world today are disabled (Yeo 2002). There is also a general consensus that disproportionate numbers of disabled people are among those living in chronic poverty. Stone offers two reasons for this:

'A considerable proportion of impairments in the majority world are the direct result of poverty, injustice, and exploitation by the minority world'.

and

'People with impairments worldwide are more likely to be poor because of disabling barriers that prevent them from getting an education, a job, access to appropriate support and services, and so forth '.

Stone (1999a, p.5).

Stone notes here that some of these barriers for disabled people are rooted in local attitudes and responses to impairment and others however are rooted in broader structural processes of poverty and injustice that produce disability (in social model terms) as well as impairment. In common with other countries, existing data in South Africa suggests that disabled people are disproportionately represented among the poor. In Pretoria, for example, a household survey indicated that in households with monthly incomes above R10,000 (Approximately £760 in 2008) fewer than 2% of individuals were categorised as disabled. However In households with monthly incomes below R800 (Approximately £60) the disability rate recorded was more than twice as high (Pretoria Government 1998).

A project briefing produced by the Overseas Development Institute of Department for International development (DFID) in 2008 in Bangladesh reported that of the 40% of the population living in poverty, 25% of these were classified by the government as living in extreme poverty. Additionally, recent economic growth had not led to a fall in poverty and least of all in the rural areas (Holmes et al 2008). These facts indicate that disabled people, who in Bangladesh live mainly in rural areas and are counted amongst the poorest, are not being benefited by economic growth and remain marginalised. Moreover, they indicate that basing action on an understanding of disability as an individual phenomenon is unlikely to improve the material position of disabled people. They also support the interrelatedness of poverty, disability and the experience of marginalisation proposed by Yeo (2006).

2.2.2 Disability, Poverty and Survival

It is known that absolute poverty (Blackburn 1991), is associated with several axes of disadvantage including disability and mortality, inadequate shelter, under or malnutrition, unemployment, illiteracy and high rates of morbidity. Elwan (1999) previously reported the connection between poor nutrition and poverty in an analysis of case studies in some developing countries, which showed that higher disability rates are associated with higher illiteracy, poor nutritional status, lower inoculation and immunisation coverage, lower birth weight, higher unemployment and underemployment rates, and lower occupational mobility. Bangladesh has the highest percentage of people living in poverty and the poorest 10% and the middle 75% of the population are acutely and chronically malnourished respectively.

Evidence of the interaction of several factors was explored in rural Bangladesh by Davis (2006) He studied the life trajectories culminating in poverty using a life history method to analyse poverty dynamics. The study was undertaken in Kushtia District in the West of the country. He uncovered the harsh and long term impact on poverty of a number of categories of crisis including illness (one of the causes of impairment) dowry, underemployment and low income, court cases, business failure, violence, crop loss, divorce, conflict and crime.

According to Groce (1999 b) begging remains the primary occupation for the majority of the world's disabled people. A recent study in Dhaka city by Manusher Jonno Foundation (i.e. Foundation for Mankind) found that about 26% of disabled persons were forced into begging by their own family members who also refused to take responsibility for their well-being (One World South Asia 2010). A sensitisation meeting for disabled people who were begging on the streets of Dhaka, was held by the Centre for Services in Disability (CSID) in Dhaka in 2008. Thirteen people and two of their attendants participated. They discussed the factors which led them to beg, and barriers encountered when begging. These related to the need to sustain an income, society's failure to meet their needs and the experience of discriminatory attitudes towards them. The following points were identified by participants:

Employment is difficult for disabled persons.

Employers pay low wages to disabled people.

Community members 'neglect' disabled beggars.

Female disabled beggars face more problems than men.

The Government has no allocation for the rehabilitation of disabled beggars.

Police demand money from beggars for staying on the street.

(CSID 2008)

Priestley (2003, p.202) writes 'Access to employment in the majority world is not only a marker of adulthood but also a matter of economic survival. Yet, in many countries, disabled people's needs for economic participation are barely recognised. Although there are a variety of different policy approaches, disabled people's economic needs have not been adequately addressed by the state and its agencies.' Khandaker (2005) suggests that employers' negative attitudes towards disabled people in Bangladesh and a reluctance to employ them is partly due to ignorance regarding their potential, and a reluctance to adapt work environments. This has implications for the role of advocacy for informed rehabilitation workers.

2.2.3 Lack of Access to Services

A further important and significant issue related to governance and disability, is a lack of access to health services particularly for people living in rural areas. Reviere and Hylton (1999, p.59) point out that in most countries, governments finance and manage healthcare services and prioritise urban hospitals. As a result rural services, often the point of access to healthcare for the poorest, are under-funded and under-resourced. In relation to Bangladesh Ahmad (1999) reported that the Government had a very marginal position in the delivery of primary health services, with the great majority of support in the arena of primary healthcare coming from international sources. Two-thirds of government expenditure on health was being used for hospital-based services, one quarter of this is for medical college hospitals and specialist hospitals. Urban poor primary healthcare needs had not been a major target for any government or private programme. Crisp (2010) reports that the majority of the services provided for the poor in Bangladesh are not sponsored by the Government but by the Bangladesh Rural Action Committee (BRAC), a non-governmental voluntary organisation, which deals with health education and other public services as well. The funds of non-governmental organisations are however limited compared to government sources of funding and this limits the development of appropriate services at primary levels.

Location of limited health resources is a significant restricting factor in accessing these services. Reviere and Hylton (1999, p.59) suggested that, even if healthcare facilities do exist, problems around accessibility, affordability and willingness to access these facilities influence their utilisation. Philips (1990) estimated that in Kenya only 10% of physicians serve rural areas while over 70% have urban private practices. In Afghanistan, only around 18% of the population had a healthcare facility within easy reach. These considerations locate access to healthcare services as an important consideration in development.

2.2.4 Summary

Section two explored material analyses of disability by addressing economic and environmental factors created by structural and institutional barriers for disabled people. This suggests that addressing disability effectively entails far more than interventions which focus on aspects of impairment. Understanding disability as a cross-cutting issue stimulates a broader range of considerations in discussions of its management. Disabled people are disproportionately represented amongst the poor. Disability as a social phenomenon is about discrimination and exclusion. Access to healthcare services is limited, not only by affordability and willingness to access them, but also by location of these restricted resources. Compared to governments, non-governmental organisations are restricted in their capacity to provide health and public services.

2.3 Section Three

2.3.1 Identity Negotiation and Stigma

Identity is a way of understanding who we are and who other people are, and in turn, who others think that they are and who others think that we are (Jenkins 2000). Therapy health professionals in the West have tended to group disabled people according to impairment labels both in educational preparation and for the convenience of service organisation. It is possible that in doing so the health services system could itself, consciously or unconsciously, have contributed to the relative 'static identities' attributed to disabled children and young people which Priestley claims 'privileges their perceived impairment status above attributes of gender, class, ethnicity or sexuality (Priestley 2003, p.193).

Other social arrangements can affect identity negotiation. For disabled youth, limited access to peer networks and youth cultures serves to restrict access to resources for identity development through 'generational modes of production'. This forces a choice between disability identities and generational youth identities (Priestley 2003, p.193). For adults additional barriers to participation in the socially valued labour of production and reproduction deny disabled people access to the social networks and citizenship rights upon which autonomous adult identities are premised (Priestley 2003, p.192). These observations suggest that identity negotiation for a disabled person is affected by several interacting factors at personal or individual, cultural and structural levels.

Goffman (1963) noted in his classic study on stigma that because society views physical impairment as a spoiled identity, stigma becomes 'a defining master identity' characterised by generalised incapacity. A negative assessment of people with established impairment has social consequences. Bickenbach (1993, p.143) suggested that disabled people share with members of 'discredited races' the experience of having 'an identifiable difference that sets them apart from "normals"'. Hahn (1988, p.26) maintained that disabled men and women have not yet been able to refute implicit or direct accusations of biological inferiority that have often been invoked to rationalise the oppression of groups whose appearance differs from the standards of the dominant majority.

Generation has however been noted as a differential in negative attitudes towards people with impairment by Priestley (2003):

'...many age-related impairments are viewed as consistent with normal biographies of ageing. Whereas impairment characteristics at birth and in childhood have long been constructed as particularly aberrant or untimely, impairments and functional limitations in old age have been more commonly constructed as a generational norm, if not a defining characteristic of the ageing process' (Priestley 2003, p.152).

In Bangladesh high levels of stigma associated with leprosy have been an important focus of interest. In the North of Bangladesh Croft and Croft (1999) reported significant reduction of stigma in areas where an awareness-raising programme had been run, compared to areas where this had not occurred. This points to the potential value of community education as a factor in reducing changing negative attitudes towards

people with visible impairment caused by leprosy. Withington et al (2003) also noted in the same area of Bangladesh that three factors were independently correlated with stigmatisation, namely female gender, those with dependents and those with a positive diagnostic skin smear test. Waldie (2002) interviewed several disabled people in Bangladesh and although negative attitudes were experienced by all interviewees those with higher social status indicated by socio-economic status, education and employment appeared more able to negotiate these successfully.

2.3.2 Culture, Language and the Negotiation of Identity

Culture refers to shared ways of thinking, seeing and doing and relates commonalities - values and patterns of thought and behaviour, an assumed consensus about what is right and what is normal (Thompson 1997, p.20). Studies of culture in the discipline of Disability Studies have adopted a broad interpretation to include symbolic aspects of human society, such as beliefs, rituals, customs, values and norms, as well as work patterns, leisure activities and material goods. Norms encompass socially acceptable rules or guidelines offering a diffuse view of culture as 'a shared way of life' (Barnes and Mercer 2003, p.89). A number of authors (Thibeault 2005; Meadows 1991; Kinebanian and Stomph 1992) have suggested that neglecting cultural relevance when providing healthcare is the most frequent oversight in international development. French and Swain (2008, p.84) comment that despite the clear relevance of disability studies (i.e. the social, political and cultural analysis of disability) to the work of healthcare professionals it remains virtually absent from their educational curriculum. This suggests that it is a very relevant topic to include in relation to the education of physiotherapists around disability particularly at a time when courses are becoming internationalised and international travel for work purposes is becoming very popular.

According to Groce (2005), societies around the world have tended to group together individuals with specific types of impairments and often have different ways of responding to them depending on the value system underlying their specific impairment interpretation. Where words referring specifically to people with impairments are used, then a consideration of meanings implied by these terms can help to locate disabled people socially within that context. Language has connections with power and can therefore contribute to the maintenance of inequality discrimination and oppression (Thompson 2003, p.71). This includes certain forms of

language which can tarnish an individual or group and carry a degree of stigmatisation. French and Swain (2008, p.187) suggest that language actually controls or constructs thinking and that disablism, sexism, ageism, homophobia, racism and are all framed within the language we use.

Terms in current use in Bangladesh for people with visible physical impairments include 'Pongu', 'Atur' and 'Lula' or 'Langra'. Pongu is the most common word is use and loosely describes anyone with a visible physical impairment. Its translation in English is 'cripple'. The more formal Bangla² word for a disabled person is 'Pokhaghat-grotho'. This word can also refer to the inability to have a job, or to function in the society due to a disease process or an accident. The formal word however is poorly understood and seldom used even by well educated individuals so 'Pongu' continues to be the term most commonly used. Until 2003 the National Orthopaedic Hospital, now named the Rehabilitation Institute and Hospital for the Disabled (RIHD), in the capital city Dhaka was also referred to as 'Pongu Haspatal'. Two other terms are commonly used for disabled children: 'Atur' and 'Lula' or 'Langra'. These describe children with physical impairments. 'Lula' means 'like a lamb'. All carry a connotation of feebleness. When these terms are used with reference to adults they carry a strong sense of derision.

For people showing signs of mental impairment the word 'pagol' is used. Its translation to English is 'crazy'. The term can be used with or without offence. When used to describe someone who is not a family member, it refers to a person whose behaviour suggests they are psychologically disturbed. Children displaying signs of mental impairment linked to conditions such as autism, cerebral palsy or Down's syndrome may also be described as 'pagol'. This word also carries negative associations linking impairment with ideas of inability, weakness and insanity. Being perceived as being ill, on the other hand, 'oshustho' or having a problem 'oshubida' is met with less social criticism and may be one explanation why parents of disabled children often use these terms to refer to their child particularly in dealing with strangers. The negative associations implied by all the terms used in Bangladesh for people with impairments

² Official language of Bangladesh

suggest that it is difficult to negotiate a positive personal identity within this social setting.

In discussing the narration of individual identities with others in a social context through the use of language Corker (2001) points out that these are situated in social spaces and historical moments. Writing about the Indian post-colonial context Ghai (2002) describes the reasoning behind the overwhelmingly negative assessment of persons with impairment based on societal values and belief systems. She also links this with language usage and writes:

'In a culture that valorises perfection, all deviations from the perfect body signify abnormality, defect, distortion. Conveying feelings of inability and uselessness, disability epitomises 'failure', and gets conceived as a personal tragedy...

'... labels such as "Bechara" (poor thing) accentuate the victim status for the disabled person and the roots of such attitudes lie in the cultural conception that views an impaired body as resulting from the wrath of fate, and thus beyond redemption.'

Her description links identity with culture, biology, and religious concepts of impairment and social positioning suggesting that a multi-faceted understanding of disability is called for. Charlton (1998) argues that many belief systems combine with paternalism to cast disability as physically or metaphysically tainted. In his view, this exists everywhere but is prominent in the least developed areas of the third world. He writes:

'People with disabilities are viewed as inferior and as the embodiment of bad luck, misfortune, or religious punishment. The disability itself primarily informs the attitude most people have about individuals with disabilities' (Charlton 1998, p.54).

The importance of recognising and addressing the impact of attitudes as social barriers to integration is an important aspect of the role of rehabilitation workers and raises the question of the extent to which this is given a focus in educational preparation.

2.3.3 Summary

The use of language in perpetuating negative identities of disabled people has been identified and examples given in Bangladesh and India. However the shaping of identity is affected by overlapping factors operating at individual, cultural and structural levels. Negative attitudes towards people with impairment in Bangladesh are mediated by different factors and appear to be changeable. The next section

examines religious frameworks around disability and the way they interact with cultural beliefs to affect responses to people with impairments.

2.4 Section Four

2.4.1 Religious Demography in Bangladesh

The link between attitudes towards disability and religious belief in Bangladesh have been noted (Momin 2003; Waldie 2002) Although covering a small land mass of 144,000 sq km (approximately equal to the size of England and Wales) the population of Bangladesh in July 2008 was estimated to be 153.5 million. Of the population 83% embrace Islam, 16% Hinduism and 1% other religions (Central Intelligence Agency, 2008). A national survey in late 2003 confirmed that religion is the first choice by a Bangladeshi citizen for self-identification, atheism is extremely rare (US Department of State, 2005). As other ethnic groups make up a very small proportion of the population, the homogeneity of the country is evident and therefore in Bangladesh Islam takes prominence as the major religious and social influence.

The Muslim population in Bangladesh is over 130 million and it is the fourth-largest Muslim population in the world after Indonesia, India and Pakistan. Sunni Muslims constitute the largest single group. There also are small populations of Shia Muslims, Sikhs, Bahai's, Animists, and Ahmadis. Estimates of their numbers vary from a few thousand to 100,000 adherents for each faith. Bengali Christians are located in a small number of communities across the country and in some indigenous (non-Bengali) groups in various areas. Buddhists are also found predominantly among the indigenous populations of the Chittagong Hill Tract (US Department of State, 2005).

A fundamental understanding is that Islam is not just a set of religious precepts, but it is a way of life (Hyde 1978). As there is no division between secular and the sacred, all of life's actions can be legitimately affected by Islamic teaching. Hirsi Ali, (2007) a female Muslim born in Somalia, writes:

'One Muslim considers Islam to be an identity: another a culture, a third purely a religion, as well as a political and social guide. But, despite these discrepancies, all Muslims share the conviction that the fundamental principles of Islam cannot be criticised.' Hirsi Ali (2007, p.1)

Although instances of strong criticism that have captured the attention of international media appeal to the Qur'an and to other texts regarded as secondary sources, it is

nevertheless emerging as a potentially powerful tool when working with Muslim communities. The introduction of its use in healthcare in the West among Muslim communities (Arshad and Fletcher 2005) raises the question of whether the impact of religious beliefs is being appropriately acknowledged and utilised within national communities.

2.4.2 Rationalising Experiences in Terms of Religious Belief

One of the fundamental beliefs in Islam is that there cannot be such a thing as a random or chance event (Qur'an, 35:2; 57:22). This includes the belief that the exact length of an individual's lifetime is established even before his or her conception. (Maqsood 2006). Life after death is a fundamental belief and life on earth is seen as a transient journey with a purpose, experienced as a series of lessons and tests influences attitudes towards suffering in general (Maqsood 2006, p.2). Muslims are encouraged to accept their difficulties with patience and humility, based on Islamic teaching that any suffering, including physical problems a person experiences, will help remove penalties in the life to come. Suffering therefore serves a purpose and is part of Allah's plan. Unlike biomedical explanations which provide an understanding of physical mechanisms resulting in impairment, Islam addresses the search for spiritual meaning in all of life's experiences including illness. Maqsood (2006) contends that despite the belief that Allah is omnipotent, Islam is not a fatalistic religion. He emphasises a need for personal responsibility referencing the following Surah:

Indeed Allah declared he would not alter the condition of humans until they changed what was in themselves.

(Qur'an, 8:53; 13:11).

He argues that the whole point of human life is a test. If Allah had pre-destined human choice this would be totally pointless (Maqsood 2006, p.52). These teachings suggest that the rationalisation of impairment in terms of religious beliefs is likely to be a prominent feature of Muslim communities.

2.4.3 Islamic Position on Disability

Bazna et al (2005) studied the Islamic position and attitude towards disability by examining the primary sources of the Qur'an and the Hadith and concluded that the concept of disability, in the conventional sense, was not found in the Qur'an. They suggest that instead the Qur'an concentrates on the notion of disadvantage created by

society and imposed on individuals who might not possess the social, economic or physical attributes that people happen to value at a certain time and place. This has some similarities with a social interpretation of disability. The Qur'an places the responsibility for rectifying this inequity on society by a constant exhortation to Muslims to recognise the plight of the disadvantaged and to improve their condition and status. Regular giving in Islam, referred to as 'Zakat', is obligatory and is one of the five pillars of Islam. The recipient categories include the poor, the needy and those who are unable to pay their debts. Disabled people qualify as recipients according to this teaching if they have unmet needs. Barnes and Mercer (2003, p.146) suggest that traditions of almsgiving in religions such as Islam and Hinduism have reinforced the idea that disadvantaged and dependent groups should be supported by charitable fund-raising and private donations. They raise the issue of the reluctance of governments within the majority world to take full responsibility for disabled citizens and suggest that this may be a contributory factor.

Ali (1994) maintains that it is possible to identify an Islamic version of the philosophy of equal rights for people with impairments. This argument is based on an incident recorded in the Qur'an detailing Allah reprimanding his Prophet for turning his back on a blind man who asked for advice and knowledge. According to this view, all members of Islamic society should be treated equally. However several other verses in the Qur'an and Hadith reveal a much less accommodating, even discriminatory attitude to disabled people (Turmusani 1998). In reality practices would appear to be very variable. Turmusani (1999) reports that in Jordan, where ninety-two percent of the population are Muslims, negative attitudes to impairment were dominant especially in rural areas. He claims that in Jordan, disabled women are often viewed as an endless burden on their families, both morally and financially, and where concern is exhibited, the motivation is protection of family honour rather than wellbeing.

2.4.4 Mixing Religious and Cultural Beliefs

In Bradford, UK, where the Muslim community constitutes around 16% of the population and numbers over 75,000 (Bradford Muslim 2005), Arshad, a Muslim chaplain at St. Luke's Hospital, maintains that most Muslim beliefs around disability are in reality a mixture of cultural and religious beliefs (Arshad 2008). Working with staff from the physiotherapy department, Islamic teachings have been utilised to promote

active involvement of Muslim patients in physiotherapy. An innovative award winning health education leaflet for Muslim patients on Islam and Chronic Pain has been developed, and used very successfully with the Muslim community in Bradford (Arshad and Fletcher 2005). The leaflet (Appendix 2), which is also available as a CD, highlights Islamic teaching on the responsibility to take care of the body as a sacred trust encouraging pro-activity and utilisation of available treatments for pain. It has proved to be very acceptable to first generation service users who often have poor levels of literacy and have a strongly oral tradition. Applying religious concepts alongside evidence-based physiotherapy practice resulted in better take up of these services by the Muslim community (Arshad 2008). The success reported by St Luke's hospital suggests that health practices could be influenced strongly when combined with appeal to religious belief.

More recently Grace et al (2008) reported on a study in Tower Hamlets in London, on lay beliefs and attitudes, religious teachings, and professional perceptions in relation to diabetes prevention in the Bangladeshi community. Tower Hamlets is one of the most densely populated, multiethnic and socio-economically deprived areas in the UK and the Bangladeshi population comprise 34% of the borough in 2001 (Office for National Statistics 2002) It also has the largest Sylheti community outside Bangladesh. This study similarly demonstrated that appeal to religious belief can play an important role in supporting health promotion in this community. It also suggested that there is potential for collaborative working between health educators and religious leaders (*imams*) who were seen as trusted sources of information and support and had access to large sectors of the community. This study also identified the powerful effect of social norms on individual behaviour and suggested that health promotion may need to be rethought for societies with collectivist histories.

In both projects, religious leaders regarded religious fatalism as a misinterpretation of Islamic teachings and were keen to address this in their role as educators. Although few lay participants expressed religious fatalism themselves, many suggested that 'other people', particularly the older generation, held such beliefs. An element of generational conflict was evident in relation to this and to other social norms and its frequency suggested that it is an important consideration in relation to the communities in Bangladesh.

Although the Tower Hamlets study findings may have been influenced by the knowledge that the London Bangladeshi community has undergone substantial social transition in the past twenty years, they nevertheless identified important social and cultural issues applicable to this research. These include kinship systems, gender aspects and role expectations, generational conflicts, especially for the role of women, and a need to question assumptions around individualism.

2.4.5 Attributing a Cause for Illness, Suffering and Impairment in Islam

Arshad (2008) reports that in Bradford it is common for Asian patients to access other forms of intervention aimed at dealing with perceived spiritual causes of impairment at the same time as attending for hospital-based treatments.

Although it is clear that Islam does not teach that impairment is a direct punishment for sin, the presence of spirits or 'jinn' and their potential influence for good or evil on human beings is a recognised part of Qur'anic teaching. In the Qur'an two non-physical entities are specifically identified namely angels and jinn. Angels do not have freewill but carry out God's wishes. Jinn are lesser spirit beings, and can be good or evil, having free will, like humans. They are thought to inhabit unclean places and can often frighten and confuse human beings by involving themselves in their lives and homes. Occasionally they attempt to possess human bodies and have to be exorcised (Maqsood 2006, p.46). They are not always malevolent however and the Qur'an (Surah 72) mentions jinn that were converted to Islam.

The belief in spirits as a causation of mental or physical illness in rural areas of Bogra in the north of Bangladesh is described by Nahar (2006):

'...Inhabitants of South Para believe that jinn inhabits on the top of tamarind, joist, boroi, banyan, trees etc. If someone goes under these trees at the noon, dusk, and the midnight, he will be attacked by that invisible creature that man has less power to cope with.'

She identifies particular behaviours believed to disturb jinn and provoke attack:

'Especially if a female goes there with unkempt hair, or if the end of her slovenly worn sari swings or welters in the ground carelessly, and if a male either urinates or leaves stool on the log of those tree, jinn living there will be disturbed. Then he will attack the man or woman by entering his body like a ray. In the beginning of the attack, he/she will fall in an incurable disease and behaves like a lunatic.' (Nahar 2006).

Similar beliefs were reported in unpublished research by Huda (2003) in Dhaka. He interviewed seven Muslim spinal cord injured patients from lower socio-economic backgrounds. These were from different districts in Bangladesh. All had accessed the services of traditional healers. The decision to do this was taken by neighbours or relatives. All identified their injury as being the will of Allah. Six out of seven mentioned the attack of a spirit (jinn) as being causative. A combination of punishment for wrongdoing and superstition around spirits was evident in most responses. Two anticipated that seeing a doctor would make the condition worse and five thought that a traditional healer could bring a cure. In 2007, DFID reported that 70-75% of the population of Bangladesh still used traditional medicine for the management of their different health problems. As there were only two doctors per 10,000 population compared to 70 traditional healers (DFID 2007), the most accessible practitioner for most villagers was the village curer or traditional healer. It was noted also that patients' relatives brought traditional healers into the spinal injury centre to 'treat' their injured relatives. This usually occurred on days when few staff were working.

According to Begum (1991) any attempts to address the needs and rights of Asian disabled people would be flawed if the issue of beliefs was overlooked. Reporting on the lives of Asian disabled people and carers in the town of Waltham Forest in Britain, she noted however that factors such as social class, educational background and religious beliefs varied substantially within the Asian community. She suggested that these factors not only affect the way disability is experienced but also shape values, attitudes and beliefs around disability (Begum 1991, p.58). She reported that carers and disabled people often internalised the attitudes prevailing in the community and thought along the same lines themselves. Her findings indicate that in many situations religious and cultural beliefs have become intertwined and confused. Her findings were comparable to Arshad's reports (2008) and supported Hirsu Ali 's (2007, p.44) contention that in Islam culture and religion are very closely connected and verses from the Qu'ran are used to legitimise many practices.

2.4.6 Hindu Perspectives on Disability

Writing about the Indian context where 80.5% population identify themselves as Hindus (Government of India 2001), Ghai (2002) asserts that the comprehension and meaning of disability in India needs to be negotiated, as it is embedded in multiple

cultural discourses. She notes that, based on the epic Mahabharata in Hindu mythology, disability implies a lack or flaw leading to significantly diminished capability. Another set of images in the same epic associates disability with deceit, mischief and evil. A third theme in the narrative depicts disabled people as suffering the wrath of God, being punished for misdeeds that either they or their family have committed. Yet another strand conceives disability as eternal childhood reinforcing the charity/pity model. This list illustrates underpinnings of a negative cultural identity. She also indicates that historically there are instances where disabled people were considered as children of God and this indicates a dignified negotiation of difference (Ghai 2001, p.27).

Ghai (2002) emphasises however that the most common construction of disability in Hindu belief systems in India uses individual model terms where impairment is not only seen as a tragedy, but is linked with ideas around due punishment for wrongdoing which is unavoidable. Her observations are likely to apply in Bangladesh where sixteen percent of the population embrace Hinduism, and close religious ties are maintained with neighbouring India. She writes:

'The common perception views disability as a retribution for past karmas (actions) from which there can be no reprieve. The dominant cultural construction in India therefore looks at disability as an essential characteristic of the individual that has to be endured to pay back for all the sins committed in the past.' (Ghai 2002, p.91).

An aspect of marginalisation particularly relevant to the Indian context is caste. Caste encapsulates politics, religion and culture, in one overarching structure that, although changing slowly, still poses a formidable obstacle. Coleridge (1993) comments however, on the imbedded notion of rank in Indian society and the implications this may have for disabled people:

'A profoundly wounded psyche is not a characteristic only of dalits. A social and religious system which ranks human beings as 'pure' to 'impure' would appear to carry a built in prejudice against disabled people who are not perceived as whole.' (Coleridge 1993, p.150).

Whilst acknowledging that there is no consensus opinion among major religions such as Hinduism, Islam and Buddhism regarding impairment, Miles (1995) agrees that in societies where these religions claim wide popular allegiance, perceived impairments

are significant for people's life chances as they are widely regarded as 'misfortunes, sent by deity, fate, karma: often regarded as parental sin' (Miles 1995, p.52).

These observations suggest that belief systems are partly responsible for inaction or even perpetuating discrimination on society's part. Pinto and Sahu (2001) suggest that in Indian culture the belief in Karma or payment for past deeds underlies an accepting spirit. They claim that the specifics of the belief system could reduce engagement with intervention programmes. For example, if chronic illness is related to actions in a past life, this may be considered to be beyond one's personal control (and therefore does not call for intervention), or because a family with a disabled child may view their situation as a test of their responsibility and duty of care, they may be less willing to take up opportunities provided by child development programmes.

A significant difference is evident between attitudes towards impairment that is acquired and impairment that is congenital. This is not in terms of belief systems but in terms of economic sufficiency:

'Indians see their children as investments for the future. When a child is born with a disability (impairment) they do not see that child as a source of support or income for the future. Hence they would rather spend their income on healthy children especially if they are male.'

'When a person acquires a disability, however, people are more sympathetic and if there is hope that the person will be fully functional again, efforts are made to provide services.' (Pinto and Sahu 2001).

This suggests that although religion and culture are important they are not the whole explanation for health seeking behaviour in India as economic constraints and gender considerations also have an important impact. For Southeast Asian families living in America, acquired disabilities were also generally less stigmatising than impairment from birth for both the individual and the family (Sotnik and Hasnain 1998).

2.4.7 Summary

Islam and Hinduism are significant influences in responses to impairment in South Asia generally. Belief systems around disability in Bangladesh appear to be a mixture of beliefs some of which have Qur'anic justification, and others which are based on superstition and local folklore. The most common construction of disability in Hindu belief systems is linked with ideas around due punishment for wrongdoing which is unavoidable. The lack of accessibility and affordability of Western medical services

may well be a determinant factor in their uptake. The availability and popularity of several other types of providers means that they also may be accessed sequentially, concurrently or even preferentially. Various interventions may be seen as complementary rather than conflicting according to local beliefs and values. Appeal to religious belief is emerging as a potential source of positive influence in healthcare and raises issues around acknowledgement of impact of religion on responses to impairment in national communities.

2.5 Section Five

2.5.1 Family and Kinship Systems

Momin (2003) referred to decision-making patterns in Bangladeshi families and indicated that family and kinship systems are an important topic in understanding the experience of disability. According to Hirsi Ali (2007, p.56), three factors characterise traditional cultural expressions of the majority of Muslims namely: an authoritarian mentality based on strict hierarchy; second, a patriarchal family structure in which the woman has a reproductive function and is expected to obey the men in the family and thirdly, the importance of the group which always comes before the individual. Social control, which is very strong, is aimed at maintaining the honour of the group. Pryce-Jones (1989, p.35) defines the concept of honour in the Islamic world as 'honour is what makes life worth living; shame is a living death not to be endured, requiring that it be avenged'. Honour and its recognition set up the strongest possible patterns of conduct, in a hierarchy of deference and respect'. She contends that the cultural expressions of the majority of Muslims are still at a pre-modern stage of development. In Bangladesh although society is changing it is clear that the rate of change is not uniform across the society with transition appearing to occur slowly in rural areas and more rapidly amongst urban, richer and more educated families.

Nahar (2006) suggests changes are taking place in family and social relations in present-day rural Bangladesh. She describes the impact of industrialisation and modernisation on the families, particularly for women mentioning a slow but significant achievement of more autonomy within the family and their better educational standards. There are now fewer joint families and more nuclear families in the village with more incidences of 'romantic' rather than arranged marriages, although these are still frowned upon. Generational changes are occurring where

attitudes of older generations are beginning to give importance to the opinions of the younger generations with a lessening of strict expectations of obedience. She notes that whereas men have given importance to women 'to some extent', male domination is still a feature.

Coleridge (1993) emphasized location in relation to disadvantages faced by women and disabled women in particular in rural India:

'Most women in India, especially in rural areas, lead an existence of extreme subservience, with very little control over their own lives. The few (mainly urban) women who have succeeded and risen to prominence in a completely male-dominated society do not indicate a general improvement, at least in rural areas

'A disabled woman suffers multiple handicaps. Her chances of marriage are very slight, and she is most likely to be condemned to a twilight existence as a non-productive adjunct to the household of her birth.

(Coleridge 1993, p.154).

His description includes reference to aspects of negotiated identity and wider social categorisations of both structural and ideational features. This suggests that an adequate theoretical basis for understanding and intervening in disability needs to be flexible enough to encompass a broad range of features. Understanding wider family and social dynamics is important, in order to direct efforts appropriately to procure positive changes for stakeholders.

2.5.2 Authoritarianism and Hierarchy in the Family and Workplace

Authoritarianism in family structures in Bangladesh, according to Maloney (1991) begins in childhood and youth and is gender specific:

'The father in a family assumes the right to control family members in a hundred petty ways ; a youth has freedom only in those areas where he has not received any specific instruction..

'A girl is told endlessly by her parents how to behave so that when she gets married she will be considered good. She is expected to learn to be submissive in her natal family so that she will carry this over to her husband's family at least for the early years of marriage.' (Maloney 1991, p.46).

Patterns of hierarchy are extended into the workplace, and to society in general where a person of higher rank is afforded the right to extract labour, service and respect from persons of lower rank and in turn assumes obligations of patronage and indulgence to them. Together these principles combine to create a society which is a 'complex maze of obligation and reciprocity most of which is tied up with micro differences in rank'

(Maloney 1991, p.43). An understanding of these and other characteristics suggests inequality in personal exchanges is normative in accordance with the family and kinship structure.

Commenting on attitudes towards healthcare providers in America, Pinto and Sahu (2001) also noted the behaviour of Indians towards healthcare providers. Respect for the authority of healthcare providers is seen as appropriate and Indians may regard their own role as passive. To dispute recommendations made by a provider may be seen as impolite and inappropriate. It is expected that providers will be confident and authoritative in proposing a treatment plan and be definite about the treatment process. Crisp (2010) raises an important point of relevance to passivity on the patients' part in developing contexts. He stresses the need to enable people to become educated so that they can think for themselves rather than perpetuating systems which disempower people by treating them as passive recipients of wisdom. This recommendation draws attention to the area of appropriate information exchange in at both individual and collective levels. His wider recommendations indicate a growing realisation of patient autonomy and the need for cultural and social attunement in order to improve health.

Groce (1999a, p.37) previously argued that rehabilitation professionals are too often trained to concentrate on clinical goals, while ignoring the larger social networks and cultural matrix in which those with whom they work live. Leavitt (1999, p.306) points out that this important theoretical domain has hardly been looked at. Barnes and Mercer (2003, p.137) contend that most people in Western societies, and particularly professionals, presume biomedical perceptions of normality are, or ought to be, universal concepts. They ignore or dismiss other cultural perceptions of impairment, causation and local and family responses. Attention to awareness of social and cultural factors is thus an important topic in the education of personnel employed in the field of disability.

2.5.3 Generational Conflicts

As this study looks at students and worker roles in the field of disability it is important to examine their social constraints in relation to the practice of physiotherapy and related healthcare work. The study referred to above in Bangladeshi community in

Tower Hamlets, indicated a number of generational conflicts evident in the role of women which are relevant to this study. The expectation was for women to remain in the home, dress modestly and prioritise family and community over independence and social freedom. Whereas in some focus groups women felt pressurised to conform to traditional norms and expectations, in others, notably with younger and second-generation women, there was support for resisting them. Exercise was seen as alien to the culture and identity of many first- and some second-generation Bangladeshis. Sporting exercise for women and older people in particular was seen as inappropriate and liable to meet with the social sanction of gossip and laughter. Whilst running in public did not in itself meet with religious disapproval, it did pose challenges to modesty, particularly for women, whose bodies would be visible to men in the community. A further point emerged which was relevant to this study. Education was a powerful force for change and was seen as a route to independence for women.

A further area of conflict for both first- and second-generation participants individualist and collectivist goals. The authors of the study suggested that contemporary health promotion in the UK was often built on assumptions of individualism and self-investment and may need to be re-thought for societies with a collectivist history. A significant comment from the Tower Hamlets study (Grace 2008) was in regard to the poor understanding of Bangladeshi culture exhibited by involved health professionals. The importance of this observation to this thesis lies in the potential duplication of this lack of understanding into courses influenced by UK personnel overseas.

2.5.4 Recognising Collectivist and Individualistic Value Systems

Iwama (2005) suggested that culture has often been treated as a secondary concern in professional discourses. He raised the issue of the appropriateness of transferring conceptual models from North to South. In his view conceptual models of occupational therapy representing Western concepts of health defined along independent, individualistic and rationalistic proclivities are questionable. His comments may also apply equally to Western models of physiotherapy practice introduced into Bangladesh, a society which maintains a collectivist value system. Jezewski and Sotnik (2001) examined how collectivist or individualistic value systems influence the manner in which people perceive their world and behave. They present a framework (Table

2.1) indicating examples of diverse cultural values and potential implications for understanding disability and accepting disability-related supports.

Table 2.1 : Collectivist and individualistic value systems

Cultural Concepts	Personal Characteristics	Behavioural Indicators
Individualism	Self expression Assertiveness Self-advocacy Self realisation	Communicating dissatisfaction with services Holding a different view of services than family unit or community Focus on the individual's unique set of talents and potential
Collectivism	Individual's existence is inseparable from the family and community Self-interests are sacrificed for those of the family or larger group Group activities are dominant	Individual may not accept transportation and work outside his/her community Supports to achieve self sufficiency not welcomed

2.5.5 Summary

The descriptions of family structure and the collectivist value systems noted within Asian communities indicate possible areas of dissonance that may emerge when individualist approaches are applied unthinkingly in these societies. This suggests that the notion of individuals as users or indeed providers of services may need to be replaced by considering families and communities. Gender issues may also be marked in terms of role expectations and generational conflicts may be evident. Location, social norms and family structures may influence how disability is experienced. The issue of education of users as a means of empowerment has also been highlighted.

2.5.6 Chapter Two Conclusion

The aim of the second chapter was to explore in more detail the socio-cultural aspects of disability in majority world contexts. In addition to considering theoretical underpinnings around the concept of oppression, materialist and idealist explanations of disability were examined. The issues discussed support the notion of a complex overlap between poverty, disability and several aspects of marginalisation. A greater appreciation of the wider issues covered could heighten social and political awareness of workers entering this field and point to the need for a comprehensive framework of disability in educational preparation. The issues raised also highlight the importance of appropriate role socialisation in the contexts considered. Professional education of physiotherapists and the training of related healthcare workers is therefore the subject of the next chapter.

Chapter Three

3. PHYSIOTHERAPY EDUCATION AND ITS ALTERNATIVES

3.0 Introduction

This purpose of this chapter is firstly to examine concepts in the professional education of physiotherapists of relevance to developing countries, and secondly to identify the rationale for the promotion of alternative approaches to training that have emerged in Bangladesh and other majority world settings.

Vigorous debate has emerged around the provision of health and rehabilitation services for the world's poorest countries. The importance of considering the context of these services was highlighted in the previous chapter. Approaches to education and training of personnel to engage in these fields which have been promoted in many majority world contexts can be broadly divided into professional education of healthcare practitioners, and the training of a variety of other alternative workers. These alternative groups of workers are referred to as mid-level workers or are named specifically according to the type of technical training they have received. This research is concerned with the assessment of the strengths and weaknesses of these different approaches within the context of Bangladesh.

The chapter is divided into three sections. The first two sections are concerned with professional physiotherapy education, and the third with examining alternative approaches to training which have emerged in the field of disability in Bangladesh.

Section one begins by identifying the most likely sources of influence on the professional education of physiotherapists in Bangladesh. The main theoretical considerations around professional education are then presented. These include concepts of profession, professional socialisation, models of professional practice and the development of an appropriate knowledge base for professional practice. The reframing of disability as a development and rights-based issue and the introduction of Community-Based Rehabilitation in developing contexts are also discussed in section one in relation to the challenge they pose for professional physiotherapy education.

Section two questions assumptions maintained by the World Confederation of Physical Therapists (WCPT) and the Chartered Society of Physiotherapy (CSP), which underpin and guide professional physiotherapy activity. These include declarations and positions adopted by both these professional bodies which impact the role of physiotherapists. Criticisms and challenges to the narrowness of focus in professional activity are raised and discussed in relation to developing contexts. A number of issues relevant to professional education are identified.

Section three is concerned with alternative training strategies which have emerged around disability in developing contexts. These have been developed not only by major international players but also by local organisations seeking to respond to high levels of need in situations of low resource. Rationale for the different training strategies, which have been developed in Bangladesh to prepare both mid-level CBR workers and groups trained around a single type of impairment are examined. A chapter conclusion is then presented.

3.1 Section One

3.1.1 Influences on the Professional Education of Physiotherapists

Although the situation in Bangladesh differs radically from the Western world, discussion of the issues related to professional education of physiotherapists in Bangladesh is based on minority world perspectives. It is important to discuss these because it has been suggested that they have had a significant impact on the education of physiotherapists in majority world settings. It is claimed that minority world curricula have been transferred to majority world settings, as have particular attitudes towards intervention in the lives of disabled people. In South Africa for example, Futter (2003) reported that physiotherapy clinical education had traditionally been based on that of the United Kingdom and was carried out in primarily in tertiary hospitals. She went on to describe specific adjustments that were made to the undergraduate physiotherapy curriculum of the University of Cape Town, aimed at aligning the course more adequately with the rehabilitation needs of the majority of the disabled population in that country. The Bachelors level physiotherapy programme implemented in Bethlehem University was founded on a British curriculum and had British professional leadership (Simister and Younis, 1999). In Bangladesh, Laing (2003)

combined three curricula from physiotherapy schools in the UK to devise the curriculum for the first BSc (Hons) Physiotherapy in Bangladesh.

Although Bangladesh has a very short history of producing physiotherapists and related healthcare workers, it is important to evaluate educational influences developments in this field thus far, particularly in relation to the relevance and appropriateness of many of these influences. The history of the physiotherapy profession in Bangladesh was outlined in the introduction to the thesis. Both major attempts to introduce professional education in Bangladesh have mainly utilised British physiotherapists working as volunteers for NGO's. This suggests that concepts and ideology underpinning professional education of physiotherapists in Britain have had significant influence on professional education of physiotherapists in this country. The nature and content of the influences on professional education of physiotherapists in the UK therefore warrants further attention in this thesis.

One of the main influences on the professional education of physiotherapists in Britain seems to be the Chartered Society of Physiotherapy (CSP) and other similar minority world national bodies. There is no evidence for this, as no research has been done into the subject, but in light of theories about the influence of curricula (approved by the CSP) and influence of role models (physiotherapists who are CSP members) one could argue this indirect link. These volunteers are considered to have transmitted individual biomedical ideologies about disability through teaching and role modelling. A lesser influence has been the main international professional body WCPT, whose guidelines provide advice to all physiotherapy organisations throughout the world.

In many less-resourced countries, disability is now approached as a development and a rights issue rather than a health issue. These changes have been influenced by the International Disability Movement and by International Conventions. The most recent and significant evidence of these influences in Bangladesh, was the ratification of The Convention on the Rights of Persons with Disabilities (UN 2006). This occurred in 2008. Accordingly attention to impairment needs is now seen as an entitlement and established as a right in the Convention (Articles 20, 25, 26). It was noted in the previous chapter that changes in law do not necessarily lead to changes in perspective or practice. Dalrymple and Burke (2006, p.286) point out that legislation around disability may contribute to a cultural shift from welfare to rights, but leave structural

and cultural barriers unchanged. They suggest that change is possible only when the link between individual and structural inequalities is understood and they advocate that the law should be used to inform practice.

Professions such as physiotherapy are challenged to make an appropriate response to changes such as this and other changes occurring in approaches to disability worldwide. This is a particular challenge to those involved in the education of beginning practitioners. Strategies in education need to keep pace with developments in the disability field nationally and internationally in order to remain appropriate preparations for practitioners they produce. Higgs and Edwards (1999, p.4) maintain that multiple factors producing changes in health professional education call for a redefinition of the type of graduates programmes aim to produce. It is significant to note that none of the volunteers involved in introducing physiotherapy education into Bangladesh had a background in professional education or in the discipline of Disability Studies, and therefore they were unlikely to be aware of the major changes occurring at international levels. It is important therefore to discuss the impact these changes may have on the education of healthcare professionals.

Perhaps the most significant change affecting disability and rehabilitation in developing countries has been in the introduction of Community-Based Rehabilitation (CBR) (Helander, Legris and Opplestrup 1989) and the changing focus within it. CBR workers were introduced into majority world settings initially as part of Primary Healthcare programmes, in response to the failure of traditional approaches to provide access to the majority of the population living in rural areas. Developing from this, a rights-based approach to rehabilitation and healthcare has gradually emerged where CBR mid-level workers are seen as a pivotal part of primary healthcare. WCPT suggests that professional physiotherapists can have a significant role in CBR. However the introduction of CBR demands a significant change in the way disability is theorised and taught. An understanding of the social model of disability upon which this approach is premised is needed in their educational preparation if they are to be involved in CBR. This would foster an understanding of structural inequality and cultural barriers faced by disabled people alongside individual impairment-related needs, which traditionally have been the main focus of professional education

In reality the numerically small professional group of physiotherapists emerging in Bangladesh has been influenced by professional influences from the Western world which are underpinned strongly by biomedical explanations of disability and concentrate on treatment techniques for people with impairment. The emphases in professional educational goals in conventional rehabilitation emanating from the West may however be inappropriate for developing contexts. A significant difference between professional education and other approaches to training is the length of respective courses. Alternative training approaches represent a short training compared to professional education. All personnel trained however in reality add to a constellation of indigenous practitioners already operating within the country. Although the research reported in this thesis prioritises the perspectives of users in assessing the strengths and weaknesses of the different providers being trained, stakeholders include all recipients of education and training and therefore their perspectives around their respective roles and their ambition in pursuing these various qualifications is also an important consideration.

Richardson, Higgs and Dahlgren (2004, p.4) maintain that health professionals need to develop the capacity to determine their professional responsibility not only towards the single case but also need to be knowledgeable about the characteristics of their specific profession in relation to other professions and to societal demands. This calls for a degree of self-awareness in understanding the position that they as professionals hold in society. Understanding the characteristics of a 'profession' is an important starting point for discussion of 'professional education'. The development of an appropriate knowledge base for professional practice is also an important consideration and both topics will be considered.

3.1.2 Characteristics of Physiotherapy as a Profession

Physiotherapy in the UK has a long history spanning more than 100 years. In the 1980s debates emerged around whether physiotherapy could be awarded the status of a profession because it failed to fit the criteria required by the definition of an ideal-type profession (Sim 1985; Hart et al 1990; Richardson 1992). The general dimensions displayed by the ideal-type of professions, medicine and law, included a unique body of knowledge and techniques which the professionals apply in their work, training necessary to master such knowledge and skills, a service orientation of professionals

and distinctive ethics which justify the privilege of self-regulation granted them by society (Larson 1977). Hoyle and John (1995) offered alternative criteria for professions which included: the achievement of a certain level of skill which can be used in non-routine situations, freedom from judgement with regard to professional practice, a professional body having both a strong public voice and autonomy from the state, high prestige and earnings and the provision of a crucial social function.

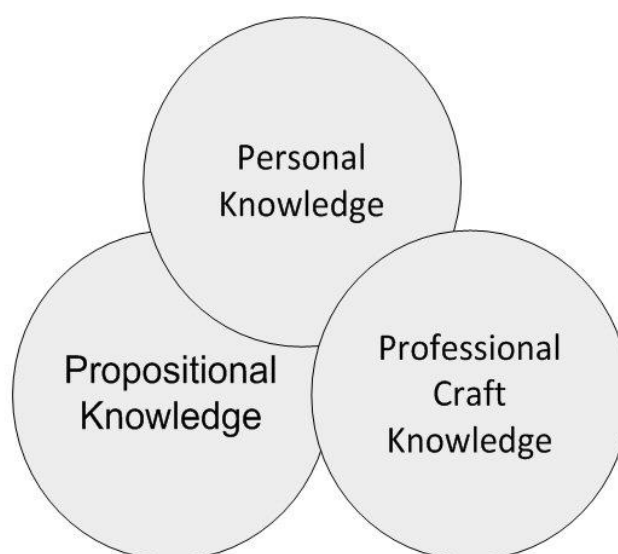
In the last two decades definitions of 'profession' have been further modified. Today, physiotherapists, alongside other Allied health Professionals, claim to be autonomous graduate practitioners enjoying government sanction with a tradition of clinical reasoning, research and evidence-based practice (Richardson 1992). Professional autonomy has not been accorded to physiotherapists in many countries, particularly those in the majority world. Considerable advances in educating physiotherapy professionals in the minority world have taken place and much greater opportunity for international sharing exists. In spite of this, many countries of the majority world lack access to even the most basic of rehabilitation services. This disparity suggests structural factors are important when considering initiatives aimed at producing and sustaining appropriate rehabilitation services in majority world contexts. The unavailability of habilitation services for children with cerebral palsy in Ghana has recently prompted the production of documentary 'The Time is Now' in which parents challenge the government to fulfil its commitments to provide access to these services in accordance with the Persons with Disability Act in Ghana (Waldie 2011). Access is dependent on the availability of practitioners equipped with an appropriate skills and knowledge and attitudes who are appropriately placed to provide services which are readily accessible to families. What constitutes an appropriate knowledge base for professional physiotherapists, and how such a knowledge base can emerge in any context will be considered further.

3.1.3 Building an appropriate knowledge base for sound clinical practice

Richardson, Higgs and Dahlgren (2004, p.4) maintain that a working knowledge of 'practice epistemology' i.e. an understanding of the nature of knowledge and the processes of generation of knowledge which underlie practice, can help to build an appropriate knowledge base for establishing practice. This is always an important step for educationalists, but deserves particular attention when health professions are

newly introduced into developing contexts. Health professionals need a working knowledge of the theories and philosophical concepts involved in their practice in order to understand what drives their actions, realise how they can demonstrate this understanding in their practice and recognise how they learn from this understanding and develop their professional practice (Titchen and Ersser 2001, pp.35-40)

Richardson et al (2004, p.2) argue that understanding practice knowledge and how it is developed is of vital importance to the quality and effectiveness of professional practice in a changing world. Professional knowledge is built on existing knowledge and upon conscious and unconscious beliefs and values held by practitioners about what they do, how they do it and why they do it (Richardson et al 2004, p.6). In order to be have relevance in different cultures professional practice should relate to existing knowledge and values held at both individual and collective levels in that context. Development of professional knowledge can be limited if the nature and dimensions of the knowledge underpinning practice are not well understood by the practitioners. Higgs and Titchen (1995) proposed a typology of knowledge consisting of propositional knowledge i.e. knowledge generated through research and scholarship and two forms of non-propositional knowledge namely professional craft knowledge and personal knowledge. This will be examined in relation to developing an appropriate knowledge base for practice in different contexts. This is shown in fig 3.1 below.



**Figure 3.1 : Forms and derivation of knowledge (After Higgs and Titchen 2000)
Taken from Titchen, McGinley and McCormack (2004, p.109).**

Propositional knowledge presently available to the global profession of physiotherapy has largely been generated from Western sources. Non-propositional knowledge is generated through practice experience and can drive new knowledge for the profession. Its first component, professional craft knowledge is knowledge embedded within practice. This comprises general professional knowledge gained from a health professional's practice experience, and specific knowledge about a particular client and a particular situation. The second component, personal knowledge includes an explicit understanding of the values and beliefs one holds outside of the codified professional values and the ability to evaluate these in light of new experiences and situations (Edwards and Delaney 2008). Higgs and Titchen (1995) stress that personal knowledge in professional practice should not be underestimated. It includes collective knowledge held by the community and culture in which the individual lives and the unique knowledge gained from the individual's life experience (Higgs, Anderson and Fish 2004, p.61). It follows that knowledge which is unique to the community and culture needs to inform practice. This will allow for development of a knowledge base appropriate for that context to emerge. As this develops it will add to the wider general body of propositional knowledge.

Higgs and Titchen's (1995) emphasis on the recognition of personal knowledge as an important dimension of professional practice is particularly pertinent to developing contexts. Foreign teachers have been instrumental in introducing their professional knowledge into countries where they have limited personal knowledge of the local culture. However, in these situations contextual knowledge available represents a rich and valuable source of knowledge. In these situations opportunities need to be created for knowledge drawn from the context to shape an appropriate knowledge base for practice. Higgs et al (2004, p.60) write:

'Professional practice is sound to the extent that it draws richly and critically on a diversity of knowledge sources. Practitioners often possess wordless understandings arising out of their cultures and communities. They also need knowledge of the physical and social worlds, knowledge of science and technology and knowledge of their own professional culture with its many hues and expectations.' (Higgs et al 2004, p.60)

Based on the integration of these different forms of knowledge the emergence of new practice dynamics specific to that context can be anticipated.

The typology above illustrates the importance of understanding and utilising knowledge drawn from nationals in the development of practice knowledge. User perspectives can also be considered to inform and be an integral part of the contextual setting upon which propositional knowledge and practice knowledge drawn from the external sources is being introduced. Capturing perspectives of qualifying national graduates will also be instructive in this respect as it will make explicit what is often tacit knowledge about the student culture and community. Professional craft knowledge drawn from students is dependent on practice experiences the students have gained, their personal knowledge of the community and culture is a potentially untapped source of knowledge where the value of practice epistemology has not been appreciated. Together these elements will allow a knowledge base to be generated, which can inform educational approaches appropriate for this context. In addition to these considerations, the importance of knowledge generated from the local environment is also discussed in chapter four.

Theory and practice play an important part in the preparation of health practitioners. Knowledge development will be determined or constrained by the way in which the relationship between theory and practice is conceptualised and interpreted (Eraut 1998). The concept of 'models of practice' is important in this regard. Models of practice are 'abstract ideas of what practice should look like if it followed a given framework' (Trede and Higgs 2008, p.32). Whether they are taught, chosen or unconsciously acquired through professional socialisation, practice models generate the principles that guide practice, create the standards that practitioners strive towards and guide performance. The next section will describe models of practice in relation to this research.

3.1.4 Frameworks of Professional Models of Practice

One 'categorisation' of models of practice is based on the work of Habermas (1972). According to this theory there are three types of interest: technical, practical and critical. Each generates a certain type of knowledge. Trede and Higgs (2008) claim that these interests shape the professional practice adopted and determine the modes of practice seen as valuable. Based on this theory, they present three practice models namely illness, wellness and capacity models representing technical, practical and critical interests respectively. The practice model influences the identity adopted by professionals and how the role of the patient/user is seen. These models are outlined in Table 3.1 below.

Table 3.1 : Three frameworks for professional practice models in health

Practice model	Illness model	Wellness model	Capacity model
Kind of interest	Technical	Practical	Emancipatory
Approach	Clinician-centred	Patient-centred	Patient-empowered

When healthcare focuses on illness and biomedical pathology (as in the illness model), the goal of care is limited to reducing deficit and pathology, or (in the wellness model), merely helping patients cope with their situation. However when healthcare is seen as a potential, the focus is on building capacity (Trede and Higgs 2008, p.34). The roles adopted by the different practitioners represent their ideology. Ideology is defined as a set of ideas associated with a particular set of social arrangements which legitimises the status quo; justifying, protecting and reinforcing both the social arrangements and the power relationships inherent within them (Thompson 1997, p.25). Ideology is important when working with marginalised groups. It is influenced by the professional socialisation experiences and, for those on shorter courses, by practice approaches adopted by the educating/training institute. Thus socialisation experiences become paramount to preparation for role and this justifies the examination of these in this research.

It has been noted above that CBR has developed into a rights-based approach to rehabilitation espousing a social model of disability. In CBR, as defined by ILO, UNESCO and WHO (1994), participants and practitioners engage in dialogue with equal power sharing and the role of the participant is interactive, participative, contributing, self-

determining. This practice model is closest in its ideology to Trede and Higgs' third practice model, the capacity/emancipatory model.

In contrast to this, traditional approaches in physiotherapy education in the UK in the 1990s prepared physiotherapy clinicians largely for illness and wellness models of practice. It is possible that these may have been reproduced in Bangladesh, in and through professional education influenced by British professionals and others. In these models the anticipated role clinicians are aiming for is that of a medical expert. It is noteworthy that not all higher education institutions in the UK now teach this traditional model of physiotherapy. Those who now follow a problem-based learning approach (Richardson et al 2007) and those practitioners in mental health and with patients with chronic illness (Waddell 1997) are beginning to follow a 'capacity model'.

The relative power of the clinician and patient varies considerably across the three practice models (Higgs and Titchen 1995). Particularly in the illness model the clinician has power and the role of the patient is passive. The role of the clinician is as a teacher/provider. In the capacity model however there is equal power sharing and the role of the patient is participative and self-determining where the clinician has a facilitative role. It could be argued that the capacity model is best suited to work with disabled people in marginalised positions in society if the goal is their empowerment. Perceptions of nationals around their roles in this research will indicate their practice models that have been assumed, indicating the outcome of the different educational approaches. These will also be linked to processes of socialisation which play an important part in professional education.

3.1.5 The Interactional Practitioner Model of Practice

More recently a practitioner model has been proposed for future health practitioners that will enable them to operate effectively within local and global contexts. It is termed the interactional professional (Higgs and Hunt 1999, p.14). This is based on a foundation of competent professional practice (i.e. technical competence) to which three further elements have been added which Higgs and Hunt (1999) claim are necessary to meet the demand of the changing healthcare arena. These are interpersonal competence, the ability to interact with and change the context of practice and the capacity to demonstrate professional responsibility in serving and

enhancing society. This model embraces key notions of competence, reflection, problem solving and professionalism combined with three other practice concepts, social responsibility, interaction and situational leadership. Table 3.2 below indicates the personal characteristics of the interactional practitioner.

Table 3.2 : Characteristics and dimensions of the interactional practitioner.
(Adapted from Higgs and Hunt (1999) page 16.)

Credible practitioner	Reflective practitioner	Competent practitioner	Situational Agent	Professional	Interdependent Team Member
Substantiation	Reflection	Being up to date	Purposeful action in macro and micro contexts	Accountable	Client-practitioner interaction
Sound reasoning and knowledge	Knowledge generation	Defensible actions	Change agent	Professional attitudes	Generic skills
Research	Self-evaluation		Social ecologist	Reliable	Interpersonal skills
			Congruent action	Mutual respect	Communication
			Flexibility		Leadership
			Assessment of needs, risks, limitations		

This model represents the attainment of competence and professionalism, but also incorporates a new vision of professional accountability and interaction with consumers and society in both local and global contexts. It represents a model which allows for flexibility and situational responsiveness in practitioners (Higgs and Hunt 1999, p.17). Higgs and Hunt propose that the interactional practitioner model is appropriate to an age of change and globalisation. It is important to note that the proposal comes from a minority world perspective, and it is not yet known if this model is appropriate to a majority world context. In a context such as Bangladesh, however, where disabled people are highly visible in the ranks of people begging, there is little doubt that at least some of these features are highly significant.

The flexibility in the model may be an important feature when preparing professionals for diverse contexts of practice such as those in developing countries but the model in itself will not guarantee a willingness in practitioners to fulfil the roles mentioned. Practitioners may perceive a specific alternative role for themselves. Specific guidance and clear leadership from educationalists and influential others regarding application of this model in practice would still be required. Professional socialisation experiences

become key influences on the outcome of educational courses and therefore will be discussed in more detail.

3.1.6 The Role of Education in Professional Socialisation

The move from student to professional graduate is not an automatic progression (Higgs et al 1999). In health professional education students participate in a process of professional socialisation. This process prepares students for the realities of the clinical practice settings through clinical placements and preparation for work and learning in multicultural settings (Edwards and Higgs 1999). The nature of the socialisation experience suggests that content is highly important and is influenced by multiple and varied sources.

Ewan (1988) suggests that students receive verbal and non-verbal messages from sources such as clinical educators, patients, other professionals and educators about professionalism and do not become professionals simply by learning theory or completing clinical experiences. The choice of 'others' to be influenced by and their behaviour is especially important (Resnick 1993). The outcome of professional socialisation can be regarded as professionalisation of the individual. Hayden (1995) considers this to be paramount in professional preparation. This raises the question of role models in situations where professions are not established. This research will indicate aspects of the socialisation experiences which have had significance for these newly qualifying physiotherapists in Bangladesh.

Apart from the foreigners teaching physiotherapy, the only other immediate source of physiotherapy role models was the handful of national physiotherapists in Bangladesh who had been educated in the 1970s. This small group of nationals all identified themselves as doctors or assistant professors, although they had attended no professional development courses since their training in the 1970s. These older physiotherapists held hospital posts or worked in private practice, and three became involved on a part-time basis in education in the 1990s. Their lack of engagement in CBR meant that there was a significant absence of any professional physiotherapy role models in CBR work in Bangladesh prior to this research. Continuing professional development in the form of short courses began in 2000, and these were led by Western trained physiotherapists. All have focused on gaining skills around

impairment rather than an engagement with wider disability issues or with community-based rehabilitation. This suggests a potentially strong influence on perceptions of role development around Western proclivities.

3.1.7 The Role of Teachers in Professional Socialisation

Houle (1980) believes that the core of all professionalisation lies with the teachers of that aspiring profession. Richardson (1999) suggested that professional education could be compared to students acquiring a lens which filters their attention to selected features of the professional world, to think about it in particular ways. She identified a lack of studies on the process of professional socialisation in physiotherapy, and little in the recent literature to indicate that students' expectations of their professional role have been of any interest to educators. She investigated new entrants' expectations of being a physiotherapist, with the intention of informing curriculum design and processes of professional socialisation in physiotherapy. Her perceptions were that students come to educational programmes with a very varied range of views on the role of a physiotherapist, influenced by a variety of experiences. She concluded that educators are challenged to guide diverse opinions and views on physiotherapy towards practice that is congruent with modern practice needs, and which includes all the components of the professional role (Richardson 2001).

This implies that educators are in a strong position to guide the socialisation of students towards an appropriate professional role. In Bangladesh, educators in the training institutes of necessity were also clinical educators in placement settings. Apart from a small number of nationals already working, most educators in Bangladesh were foreigners with little previous exposure to the healthcare system, or to the lived experiences of disabled people. The shortage of teachers meant that foreigners were given little, if any, orientation time on arrival and were unable to develop any degree of fluency in the language as a vehicle of communication in order to gain a greater understanding of user perspectives.

One of Dawson's (1997) main recommendations, based on her experience of establishing professional education of physiotherapists in Palestine, relates to the cultural and social context in which educational programmes are set. She maintains that if educators come from a different culture they should make an in-depth survey of

customs, conditions and expectations of professionals, funders and clients before designing a curriculum for any ethnic group. Despite this careful preparation, she reported that local staff in Palestine still saw the curriculum as a foreign import.

An important contribution to understanding professional socialisation comes from the field of organisational behaviour. A central assumption in this field is that organisations influence their members and can routinely change newcomers' attitudes and values (Arnold, Feldman, and Hunt 1992). However impression management theorists have suggested that individuals may very well on the surface conform to organisational standards while keeping intact their own personal attitudes and points of view (Gaudet 1983). The implication of this is that the values and professional orientations that individuals bring with them into the educational organisation are more important than what they can learn during socialisation. Support for this idea is given by Zeicher and Gore (1990) who described professional socialisation as occurring in three stages: Anticipatory socialisation, formal training and post qualification experiences. Middleton (2007) also considers professional socialisation to be a multi-staged, multi-phased and fragmented process, which does not stop on completion of formal training.

In the anticipatory phase, individuals get a sense of the profession from previous experiences. It also includes images built up from observation (Middleton 2007). The formal training phase comprises the formal studies required to qualify for a professional role. The curriculum, referred to as a unique body of professional knowledge, is often considered a requisite for claiming professional status. Middleton (2007) states that the curriculum, teaching methods, level of classroom activity, practice activities and exposure to the workplace all contribute to socialisation. The post-qualification phase includes formal training courses, postgraduate qualification and informal learning.

The implications for this study are that factors influencing anticipatory socialisation in Bangladesh may be the most important factor in professional socialisation, if superficial conformity to organisational standards are occurring, and these will be shaped by a social context which is very different to that in the West. It will therefore be important to understand this phase in particular.

3.1.8 Possible Influences of Anticipatory Professional Socialisation

Cusick (2001, p.91) suggests that in becoming a professional, individuals engage in the process of 'role taking' and 'role making'. She suggests that once the decision has been made to become a professional, energy and actions are directed towards developing the professional role. However, in a context where physiotherapy professionals were not an established professional group, what influences notions of the role of a physiotherapist is unclear. In Bangladesh in 2007 a population based, nationally represented, survey was done covering all types of active healthcare providers in both formal and informal sectors (Ahmed et al 2011). This was aimed at providing data on available healthcare resources in order to inform policy-makers of the changing healthcare needs of the population. The survey indicated that the government classified physiotherapists as a technically trained group. They were included in the results as paramedical workers who were semi-qualified and their numbers were minimal. A summary of the results showing the density of all active providers of healthcare per 10,000 population is shown in Table 3.3 below.

Several important factors emerged. Qualified healthcare practitioners included doctors, nurses and dentists only. There were 2.5 times more doctors than nurses. This ratio fell far short of the international standard of three nurses per doctor. The large numbers of doctors compared to technologists also noted was also described as a 'gross imbalance' (Ahmed et al 2011). Several other interesting facts emerged from the analysis including the observation that the poor and disadvantaged mostly seek healthcare from non-qualified providers in the informal sector. Additionally, although 75% of the population of Bangladesh were quoted as living in rural areas, the distribution of qualified healthcare professionals showed an overwhelmingly urban bias.

In relation to influences of the anticipatory socialisation phase of professionalisation, the survey indicated that the most visible professional healthcare role was that of a medical doctor. A male gender bias was evident in this group. This suggests that the decision to become a professional physiotherapist by pursuing a baccalaureate qualification, in the absence of an established profession of physiotherapists, may be influenced by the role modelled by predominantly male doctors.

Table 3.3 : Density of all active healthcare providers per 10,000 population in Bangladesh in 2007. Adapted from: The health workforce crisis in Bangladesh : shortage, inappropriate skill-mix and inequitable distribution(Ahmed et al 2011)

Type of provider		Other points of note
<u>Traditional Healers</u> Kobiraj Faith healers Total	 32.7 31.5 64.2	'Kabiraj', practice is based on diet, herbs, and exercise. They are mostly self-trained, but some may have training from government or private colleges of Ayurvedic medicine. Faith healers are non- secular.
<u>Homeopaths</u> Qualified Unqualified Total	 3.4 2.5 5.9	Homeopaths: mostly self-educated, but some possess a recognised qualification from government or private homeopathic colleges.
<u>Unqualified allopathic providers</u> Village doctors Drug vendors Total	 12.5 11.4 23.9	Village Doctors : (predominantly male) received training from a few weeks to a few months in formal institutions, GO or NGO, and were mainly concentrated in rural areas. Vendors at drug retail outlets were uniformly spread across the country. Most have had no training in dispensing, or diagnosis and treatment.
<u>Semi-qualified allopathic providers</u> Para professionals CHW –govt CHW –non govt Total	 1.0 3.2 39.7 42.9	Para-professionals were mainly concentrated in urban areas and comprised Medical Assistants (3yr training), Midwives (18mths training), Lab. Technicians and Physiotherapists. Community Health Workers (CHWs) (predominantly females) were mainly concentrated in the rural areas and have variable lengths of basic preventative and curative healthcare training. They include traditional birth attendants who provide delivery related services at home only..
<u>Qualified Healthcare Practitioners</u> Doctors Dentists Nurses Total	 5.4 0.3 2.1 7.8	Distribution overwhelmingly favours urban areas. There were 2.5 times more doctors than nurses M:F ratio doctors 4:1 Nurses 1: 9
<u>Other</u> Circumcision practitioners, ear-cleaners, tooth extractors	1.7	Survey Conclusion : Bangladesh is suffering from a severe human resources for health crisis in terms of a shortage of qualified providers (when measured against the WHO estimate for achieving MDG targets), inappropriate skills-mix and inequity in distribution.

Considering the formal training phase of professional socialisation the propositional knowledge available to students (Higgs and Titchen 1995) depended on the availability of library resources in the training establishments. The limited development of these in Bangladesh meant that access to empirical knowledge was minimal. The students largely depended therefore on 'received knowledge' from their teachers augmented by non-propositional knowledge gleaned through professional craft and personal knowledge. As teachers were mainly British volunteers, a scrutiny of British influences on their professional knowledge base is justified. Although in principle the World Professional body, WCPT can influence and guide, it does not function as a sending

body for expatriates and its influence is nominal only. Of greater influence is the national professional body's position of influence on volunteers' educational preparation, which in Bangladesh was from the UK's CSP. Assumptions around physiotherapy and positions adopted on disability and rehabilitation reflected in these professional bodies can be considered to be key influences on professional physiotherapy education in Bangladesh. These will therefore be critiqued in the next section with particular with reference to their applicability in Bangladesh and other majority world settings.

3.1.9 Summary

It is claimed that the key sources of indirect influence on professional education of physiotherapists in Bangladesh has been the CSP in the UK and the WCPT. Based on minority world perspectives the main theoretical concepts around professional education and professional socialisation of physiotherapists have been described. Non-propositional knowledge is generated through practice experience is seen as an important form of knowledge in establishing an adequate knowledge base upon which to build professional practice in new contexts. Changes in thinking around disability internationally poses challenges to professional education in developing world contexts in particular. The introduction of CBR and the adoption of a rights-based approach to disability in developing contexts call for changes in professional socialisation experiences. However, the use of foreign teachers with little or no experience in CBR within Bangladesh suggests areas of inadequate preparedness for this role. The impact of the varying influences on professional physiotherapy roles will emerge in the research findings. The anticipatory phase of professional socialisation has been highlighted as an important aspect of socialisation with respect to this research enquiry.

3.2 Section Two

3.2.1 WCPT and the Focus of Professional Education and Practice

The World Confederation for Physical Therapy (WCPT) acts as the sole international voice for physical therapy/physiotherapy and represents more than 300,000 physical therapists worldwide through its 101 member organisations (WCPT 2009). WCPT is committed to forwarding the physical therapy profession and its contribution to global

health. It encourages high standards of physical therapy research, education and practice throughout the world (WCPT 2009). As developed nations have been predominant in leading WCPT from its inception in 1952, minority world perspectives are likely to have influenced policy and direction.

The Declaration of Principle : Education (WCPT 2009), states that curricula for physical therapy education should be relevant to the health and social needs of the particular nation. In light of this it is relevant to consider definitions of the nature of physiotherapy, disability, rehabilitation and roles envisaged by WCPT for physiotherapists generally. WCPT endorsed the ICF at its general meeting in 2003 (Sykes 2011). Since that time it has incorporated ICF principles and definitions in its documents (Harms 2011). However, the description of the nature of physiotherapy intervention by WCPT (2009) has not changed since this endorsement, suggesting that the revised perspectives on disability in the ICF have had little impact on the role envisaged for physiotherapists.

WCPT (2009) defines the nature of physical therapy as being ‘concerned with identifying and maximising quality of life and movement potential within the spheres of promotion, prevention, treatment/intervention, habilitation and rehabilitation’ (WCPT 2009). It describes physiotherapy/physical therapy practice as being ‘directed towards the movement needs and potential of individuals and populations’, and states that ‘Populations may be nations, states and territories, regions, minority groups or other specified groups’. Underpinning the practice of physiotherapy/physical therapy practice is the claim by WCPT that ‘functional movement is central to what it means to be healthy’ (WCPT 2009). Based on the assumption of the centrality of functional movement to wellbeing, the body and its movement deficits are the main focus of professional intervention for physiotherapists.

In situations which are highly dependent on physical labour, and where welfare systems are inadequate or non-existent, the ability to move may be crucial to survival of a family especially where the person affected is the breadwinner. Where the natural terrain is hostile and transport systems underdeveloped, even a minor reduction in agility may result in a significant limitation of activity for the majority of the population. It is not difficult therefore to appreciate why the WCPT describes the

capacity to move as an essential element of health and well-being, and a legitimate focus of concern to those who work with disabled people.

WCPT(2009) states that physical therapy interventions are implemented and modified in order to reach agreed goals, and may include manual handling; movement enhancement; physical, electro-therapeutic and mechanical agents; functional training; provision of assistive technologies; patient-related instruction and counselling; documentation and co-ordination, and communication. These are delivered at an individual level. Interventions may also be directed towards promoting the health and wellbeing of individuals and the general public/society. These emphasise the importance of physical activity and exercise. Interventions may also be directed towards modifying environmental, home and work access and barriers to ensure full participation in one's normal and expected societal roles. They may also be aimed at prevention of impairments, maintenance of existing function or in keeping with the ICF framework, directed towards participation restrictions. Targeting 'disability and injury' and interventions which promote and maintain health, quality of life, workability and fitness in all ages and populations are also legitimate (WCPT 2009).

Higgs, Neubauer and Higgs (1999, p.35) argue that policy making should not be a process confined to politicians and that health professionals are well placed to consider actual and potential effects of existing policy and thus could have an influence at a structural level. The WCPT (2009) does suggest that physiotherapists may also influence policies and public health strategies, but examples given suggest this should relate to issues around movement and bodily deficit rather than at structural or cultural barriers resulting in inequality or discrimination.

Criticisms have been raised about the value of this very specific focus of attention around the body and movement deficit by a number of authors. Thompson (2001, p.11) writes:

'Practice which does not take account of oppression and discrimination cannot be seen as good practice, no matter how high its standards may be in other respects. For example, an intervention with a disabled person which fails to recognise the marginal position of disabled people in society runs the risk of providing the client with more of a disservice than a service' (Thompson 2001, p.11).

Hammell (2006) suggests that therapists play an active role in maintaining and perpetuating disabling environments, or an active role in changing them. She is critical

of the political neutrality often exhibited by therapists towards disabled persons' social position. In her view striving to change dimensions of individuals so that they can better fit with segregated environments rather than striving to change dimensions of the environment in order to counter discrimination and equalise opportunities represents a political act in itself. She writes 'Acquiescing to the inequities of the status quo might be politically conservative, but it is political' (Hammell 2006, p.143). Schriener (2001) maintains that avoiding confrontations with structural and attitudinal barriers that discriminate against disabled people attracts to the rehabilitation professions those people who are more interested in modifying individuals than achieving social justice.

WCPT (2009) declares that physiotherapists have a role in achieving social justice in relation to influencing policies promoting equity in access to services. Ethical Principle 8 (WCPT 2009) states 'Physical therapists have a duty and an obligation to participate in planning services designed to provide optimum community health services' and 'Physical therapists are obliged to work toward achieving justice in the provision of health services for all people'. How these principles should be outworked in practice is less clear. To adhere to these principles requires a clear understanding of community needs and infers educational preparation should have these in mind. Understanding disability in terms of social oppression, rather than individual deficit, could help raise awareness of social injustice and inequity in provision and promote activities aimed at more equitable access. Despite these declarations WCPT has no legal power to enforce national associations to engage with these issues. Directives may however come from respective governments. In Bangladesh the Disability Welfare Act became law in 2001 and included a schedule on both Healthcare Services and Rehabilitation for disabled people. By 2006 however the director of the National Forum of Organisations Working in Disability (NFOWD) reported:

'The present rehabilitation infrastructure remains weak, especially at community level. Of the limited opportunities for rehabilitation, almost all are institutional based programmes situated in urban centres. This implies that the current rehabilitation infrastructure is ill equipped to meet the needs of the majority of people with disabilities in the country, most of whom not only live in rural areas, but who are also unlikely to have sufficient resources to gain access to even basic rehabilitation services.' Rahman (2006)

This situation suggests that changes in the law have done little to impact infrastructures around provision of therapeutic services. A number of factors at structural and cultural levels may need much greater attention in educational preparation if physiotherapists are to fulfil their professional responsibilities in the society by working for 'justice in the provision of health services for all people' as WCPT recommends. The lived experiences of participants in this study will help to establish an understanding of the impact that rehabilitation services are making in the lives of disabled people.

Bangladesh's signing of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) in 2006 and later ratification in 2008 indicates a further change in the law has taken place. In the Convention disability is perceived as primarily a social problem and a human rights issue which demands a social and political response (UN 2006). Rahman (2006) has suggested that international charters /declarations/treaties are often signed without an in-depth understanding and there is a lack of commitment to fulfil these. Implications for possible changes in education and practice around disability emerging from the ratification of UNCRPD have yet to be enunciated.

At its simplest level, moving to fulfil a rights-based model as a basis for intervention will require that an awareness of the rights of disabled people is included in professional educational preparation. A useful avenue of enquiry in the research will be the status of practitioners' knowledge of rights of disabled people and users' understanding of their own rights as contained in the Disability Welfare Act of 2001.

3.2.2 Influences from the Chartered Society of Physiotherapy

It has been suggested that the major influence on education of Bangladeshi physiotherapists has indirectly been the CSP in the UK. In the CSP's Curriculum Framework (2002) physiotherapy is described as 'a healthcare profession concerned with human function and movement and maximising potential.. which uses physical approaches to promote, maintain and restore physical, psychological and social well-being, taking account of variations in health status' (CSP 2002). Definitions of both impairment and disability used in this framework correspond with definitions used in the ICIDH1, where impairment is defined as 'the loss or abnormality of psychological, physiological or anatomical structure or function, and disability as 'any restriction or

lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being' (WHO 1980, p.29).

This means that CSP has largely retained an individual model of disability, whereas WCPT has aligned with ICF in seeking to combine individual and social models of disability. (These models were discussed in Chapter One). In 2008, CSP's international advisor drew attention to the failure of the CSP to engage with the social model of disability and to the minimal publicity that current WHO and WCPT policy discussions have had in professional discourse on disability in the UK. The CSP's International Policy and Strategy Statement (CSP 2009) stated for the first time, as an objective, that it will promote awareness and understanding of the social model of disability and a closer engagement with disabled people's organisations in order to promote patient care and workforce practices based on ethical, environmentally responsible, rights-based principles. However the continued strength and influence of the individual model of disability in professional physiotherapy education in the UK suggests that this may also be reflected in physiotherapists elsewhere who have been taught by British professionals. If this understanding of disability is held in Bangladesh it will subsequently influence thinking and interventions around disability. Likewise, other groups of related healthcare workers will reflect theoretical perspectives adopted in their respective training bodies. These will be described later in this chapter.

3.2.3 Questions Around Improving Quality of Life.

UK's professional body, CSP, has recently re-defined physiotherapy as an intervention which maximises quality of life: 'Physiotherapy encompasses a range of interventions, services and advice aimed at restoring, monitoring, and improving people's function and movement and thereby maximising the quality of their lives' (CSP 2008). This statement maintains the central idea that functional movement has a major impact on quality of life.

The concept of 'quality of life' as it is used in both WCPT and CSP definitions is problematic because it lacks clear definition and no uniform system of measuring it has been agreed (Roy 1992). Despite the assumption that maximising quality of life is linked with movement potential, perceptions of quality of life have not been shown to correlate with the degree of physical function or the extent of physical independence

(Hammell 2004). Respecting clients' autonomy is however recognised as a positive contributor to quality of life (Treece et al 1999).

The evidence above suggests that maximising movement potential is a faulty premise upon which endeavours to improve quality of life should be based. A number of writers (Ville et al 2001; Vogel et al 1998; Westgren and Levi 1998) have drawn attention to the fact that pain has a greater impact upon the of experience of quality of life than does the extent of physical impairment, level of function or degree of independence. This again calls into question soundness of WCPT's and CSP's assumption that movement is a central issue in what it means to be healthy. Basic assumptions made by physiotherapists around quality of life may need to be re-examined if the goal of intervention is to improve quality of living. The research will elucidate user experiences of physiotherapy services in Bangladesh and indicate how interventions are perceived in that context.

3.2.4 Rehabilitation in Physiotherapy

Following on from an individual model of disability, the traditional rehabilitation paradigm assumes a biomedical clinical orientation (Leavitt 1999, p.4) attracting strong criticism: 'By defining disability as a medical/individual problem the rehabilitation professionals have delimited their mandate "to the cure or restoration of the disabled individual to as nearly normal existence as possible" (Groce and Sheer 1990) ; somehow viewing this as an adequate, useful and benevolent response to disability' (Hammell 2006, p.59). Swain et al (2003) suggest that there has always been a limited view that rehabilitation is a process of teaching skills to enable an individual to attain the highest level of physical independence and agrees that this assumption appears to be emerging naturally from thinking, which assumes disability to be result of individual deficit. This view is also held by a number of other health professions, for example, rehabilitation was perceived by some nurses to be physiotherapy (Walker 1995). In contrast to this understanding the UN Standard Rules, endorsed by WCPT (2009) describe rehabilitation as

'a process-enabling greater independence aimed at enabling people to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence.'

'It may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation...It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation' (United Nations 2006b).

This wider definition of rehabilitation used reflects a breadth of understanding which contrasts with the narrow idea prevalent in physiotherapy education and practice in the UK that rehabilitation is concerned primarily with the enhancement of physical function.

The danger in having a narrow understanding is that it can lead to the failure in practitioners to even consider how rehabilitation might be related to vital issues such as employment and income generation and limits thinking around professional role development. Transferred to developing contexts this may have serious consequences for users.

3.2.5 The Neglect of Subjective Experiences in Rehabilitation

A related aspect of rehabilitation concerns the engagement with identity negotiation as a disabled person. In Western contexts Toombs (1995) and other researchers (Becker 1993; Murphy 1995; Carpenter 1994) maintain that a disruption of one's physical condition is experienced as a disruption not only of the body but of one's self. Both medical and rehabilitation professionals have been criticised for their tendency to objectify the body and ignore the subjective experiences of disabled people (Paterson and Hughes 2000). Specific criticism of rehabilitation professionals has been voiced regarding their role in preparing individuals for reintegration into society. Murphy et al (1988, p.24) claimed that rehabilitation establishments are 'ineffective in preparing people for the social conditions they will face'.

Theorising about the body in relation to the self is included in the educational preparation of professional physiotherapists (CSP 2002) however application of this knowledge is rarely applied in any depth in practice. This disengagement with social factors impacting the personal lives of disabled people is rooted in the historical development of the profession in the UK. Hammell (2006, p.107) noted that traditionally the rehabilitation professionals have had little dialogue with social sciences and humanities, aligning themselves with the biological sciences and especially medicine. This close alignment with medicine alone, if transmitted to

students in Bangladesh will impact the role that physiotherapists envisage for themselves and also their professional identity as a group. If public recognition is sought solely as 'medical professionals' then diagnosis and treatment may take precedence over supporting the negotiation of a positive identity in order to enable disabled people to challenge inequality and discrimination and may not be seen as part of their role. The research will illuminate whether this is the case from user accounts.

According to Ghai (2001) the experiences of poor disabled people in India influences their social status and identity. 'With practically no access to education and training, they are forced to live a life marked by extreme defencelessness' (Ghai 2001, p.29). Ghai suggests if rehabilitation workers were routinely supportive towards the negotiation of a positive identity the seemingly overwhelming task to change this situation may diminish. For physiotherapists working in Asia this is an important consideration. It is particularly relevant, for example, for persons affected by leprosy where stigma is associated with loss of income and debilitation (Calcraft 2006). The research findings will indicate whether educational preparation and training approaches impact include identity negotiation as a concern integral to the therapeutic endeavour.

3.2.6 Questioning Ideologies Underpinning Physiotherapy Practice

Ideologies of independence and normality are implicit in Western physiotherapy practice and both ideologies have drawn criticism. According to Oliver (1996, p.104), an ideology of normality which permeates most rehabilitation practices often goes unrecognised by professionals and their 'victims' alike. Together with a failure to address issues of power in rehabilitation, Oliver maintains that 'their existence gives rise to a set of social relations and range of therapeutic practices that are disabling for all concerned' (Oliver 1996, p.104). He argues that the failure to acknowledge these ideologies results in practices that are oppressive to disabled people and constitute an abuse of their human rights. He suggests that properly addressing these issues will make rehabilitation a more appropriate enterprise.

Critiques of traditional rehabilitation practices do not rule out the benefits of addressing impairment and its effects (such as pain and reduced bodily function) but rather raise questions around issues of power within the relationship of professionals

and patients and question the ideology of normality underpinning many of their practices. Oliver (1991, p.89) supports a vision of integration which is based instead on promoting a more humane society, one that positively values and includes difference.

Hammell (2006) questions the assumption that the goal of independence in therapy is one to which all clients aspire or ought to aspire pointing out that few therapists have maximised their own functions even. Furthermore whilst independence has been ideologically constructed as the 'norm' it is evident that interdependence is more usual. People from South Asian countries place much higher value on interdependence (Gibbs and Barnitt 1999) than independence. This raises a question around the value of imposing independence (as opposed to interdependence) as a therapeutic goal particularly in cultures typified by traditions of reciprocity and mutual obligation. This suggests a need to frame agreed goals of rehabilitation within an understanding of culture.

Both Finkelstein (1993) and Oliver (1996) highlight the need for social justice in enabling inclusion rather than social manipulation which controls disabled people's lives. Hammell (2006, p.197) suggests is that an overarching concern of rehabilitation with functional movement is an inadequate approach and needs to be balanced in educational preparation with attention to social factors impacting the lives of disabled people: 'An individualised function- obsessed approach to rehabilitation is an inadequate response to the circumstances that confront disabled people in their everyday lives'. In countries where work is an essential part of economic and social life then return of physical function may be seen only as a means to this important end. Coleridge (1993) noted that disabled people in developing countries often placed their need for income at the top of their list of priorities. Housing, transport and sex were also given a higher priority than rehabilitation. Hammell (2006) suggests making a distinction between activities which can be deemed treatment, aimed at physical cure, and those concerned with the rehabilitation endeavour, which are concerned with living. She argues that re-gaining function is for a purpose, and therefore, consideration of what makes a person's life worth living needs to be addressed as an essential part of the rehabilitation process.

3.2.7 Outcomes of Rehabilitation

Outcomes of rehabilitation routinely assessed by physiotherapists in Western contexts are often evaluated in terms of levels of restoration of physical function. A focus on function alone rather than on enabling a person to pursue their interests (which in poorly resourced countries often entails striving continuously to survive) may legitimate a failure to confront social barriers faced by disabled persons. It is also out of line with WCPT'S recommendation that services developed should be appropriate to the health and social needs of the community. Achieving this may point to a need to follow Thompson's (2003, p.40) suggestion that people workers (including professional therapists), need to develop emancipatory practice, a form of practice that explicitly addresses inequality, discrimination and oppression. This would require a substantial rethinking around outcome evaluation uncoupling it from measurements of physical dimensions related to impairment. Likewise Thompson's (2003, p.108) recommends 'taking on board wider cultural and structural factors, in order to avoid overemphasising individual factors and thereby working on the basis of a distorted picture of the situation.'

Lyons et al (2002) noted that the idea of a life worth living, given the onset of impairment, is strongly influenced by perceptions of being able to exert control over one's own life. Coleridge (1993) points out that political social and economic forces all play a part in enabling people to gain meaningful control. Power is closely linked with having control. This suggests that interventions, which enhance possibilities of regaining meaningful control, may need to engage not only at a personal level but also with power dynamics within wider the society. This idea can be linked with the model of an interactional practitioner (Higgs and Hunt 1999, p.14) in which the professional role envisaged includes engaging with social and environmental factors impacting on the user's life.

The experience of powerlessness may be critical for impoverished families in under-resourced countries when interacting with professionals who may wield power as 'gatekeepers' of important resources such as access to loans. Taylor (2005) surveyed the socio-economic position of patients with spinal injury in Bangladesh in The Centre for the Rehabilitation of the Paralysed (CRP) and reported that eighty percent of families were unable to pay for treatment without selling items of capita. The loss of

regular income frequently precipitated long term financial crisis and placed families in positions of powerlessness and dependency on personnel with influence over authorisation of loans.

It is important to note here that criticisms are not around the question of the need for physical interventions. Lang (2000) has suggested that the problem lies in the nature of the social conditions and relationships that are encountered when disabled people and the medical profession interrelate with each other. French and Swain (2008) also agree that disabled people want and expect the best medical care available to them, if and when it is necessary, but stress that they also expect to be treated as equals and as full participative citizens in control of their own lives.

Gaps in status between professionals and users has been noted as an important factor in considerations of power. In a hierarchical society such as Bangladesh, the power dynamics between users, and the various levels of rehabilitation workers are influenced in part by choice of candidates for education and training processes. Leavitt (1999, p.11) noted that practitioners do not usually come from poor backgrounds and need to recognise that socio-economic status profoundly influences the everyday existence of a disabled person who does. This raises the question of selection of appropriate candidates for training who display empathy and understanding of recipient's position.

The research should indicate whether the candidates selected do demonstrate sensitivity to these power dynamics. By virtue of the high entry requirements, the BSc professional courses may mean that students are recruited from backgrounds that are far removed from the poorest populations and this may affect both the nature of relationships with users and indeed their willingness to engage with poorer and disadvantaged communities. Students on government courses, however, where educational fees are less, may be themselves closer in status to many of their patients and this may be indicated in the relationships between them. The focus on empowerment in the capacity model of practice suggests it may be useful as a practice model in developing contexts. The interactional model of practitioner discussed includes mutual respect and excellent interactional skills and may also be of value.

For many disabled people the search for empowerment is generated by experiences of disempowerment however this is manifest whether through poverty, segregation, institutionalisation, institutional abuse and discrimination and restriction on life choices (French and Swain 2008, p.139). French and Swain (2008) see empowerment as a process that promotes people's prediction and control over decision-making that shapes their lives. They suggest four principles that empower. These are, firstly, the questioning of power relations, organisational structures and dominant ways of understanding that limit people's life choices and control; secondly, seeing empowerment is political as well as personal; thirdly, promoting struggle against man-made suffering; and fourthly, recognising that empowerment is 'taken' by those who are powerless rather than 'given' by those who have power. Within a strongly hierarchical society such as Bangladesh empowering relationships may appear in some ways to be counter-cultural and need careful attention to engender.

3.2.8 Professional Education for CBR Involvement

CBR was launched officially in 1974 and adopted as WHO policy in 1978. The necessity for CBR involvement to be embedded in professional physiotherapy education appropriately is an important consideration in contexts where there are insufficient professional staff and other resources to fulfil the rehabilitation needs of communities. Community Based Rehabilitation (CBR) deserves careful attention as it was founded with the intent to make rehabilitation services available to a larger proportion of previously un-served persons (Helander, Legris and Oppestrup 1989).

Since its adoption, many different interpretations gradually emerged and with them a plethora of organisational models. This variation in organisation prompted the publication of a joint position paper in 1994 by International Labour Organisation, (ILO), United Nations Educational Scientific and Cultural Organisation, (UNESCO) and the World Health Organisation (WHO). The joint paper gave the following definition of CBR, which has been the most commonly accepted definition in use since 1994:

Community Based Rehabilitation is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services. (ILO, UNESCO and WHO 1994)

Whilst CBR was introduced as an alternative approach to service delivery in order to reach rural and marginalised groups with rehabilitation services, it has increasingly been seen as an instrument for promoting empowerment. Participation of disabled people and their families gradually came to be regarded as an integral part of CBR, rather than an optional extra. The key feature enabling this has been ownership of programmes by the community, as represented by the local government or authority.

WCPT has extended their description of physiotherapy roles to describe a role in Community Based Rehabilitation (Bury 2003). Specific roles for physiotherapists include teaching other workers. WCPT (2009) states:

Physical therapists are equipped to work in both urban and rural settings and have an important contribution to make in CBR: By providing interventions aimed at health promotion, disease prevention, treatment and rehabilitation; by educating and transferring skills to other staff, carers and the community to achieve the fulfilment of physical therapy and patient/client goals; through consultancy, advice, support and supervision to other health, education and social care/service personnel; as initiators and managers of programmes; and as policy advisers to Governments, Non-Governmental Organisations (NGOs) and Disabled People's Organisations (DPOs) WCPT (2009)

This move anticipates that appropriate professional educational preparation for CBR will be made available. The absence of experienced teachers of CBR is not directly addressed and role development based on an understanding of social model of disability inherent in present definitions has received scant attention despite the prominence attributed to CBR in international discourse.

Maas (1997) sought to identify requirements for professional physiotherapists working in CBR in Palestine and she highlighted the need for good communication skills. Also advantageous were knowledge of the community and its disabling practices. Necessary skills included physiotherapy, problem solving, awareness raising, teaching, counselling, and advocacy, de-professionalisation and de-mystification of medical information. This list calls for a broad based workers who appreciate the impact of power dynamics in interactions and are equipped to engage at many levels. Maas's work was based in a war zone the Middle East in a mainly Islamic culture. Although this is geographically dissimilar, many other features are similar and her work may have relevance to this research.

Maas (1997) identified the fact that physiotherapists needed to be able to promote empowerment and encourage participation by disabled people. A lack of status for physiotherapists working in CBR (Bury 2003) has been identified by WCPT and suggests a possible tension between professional power and the community ownership of CBR which may emerge in the research.

3.2.9 Summary

This section has critiqued definitions, assumptions and ideologies underpinning physiotherapy as provided by the WCPT and CSP. It is argued that these have indirectly influenced educational preparation of professional physiotherapists in Bangladesh. The nature of relationship between professionals and users has been considered, particularly in relation to candidate selection and CBR principles. The relevance of issues raised to the research proposed has been identified and suggestions around the need to align rehabilitation endeavours with user priorities raised. Emphases in professional physiotherapy practice in Bangladesh resulting from educational preparation will be exposed in the research findings.

3.3 Section Three

3.3.1 An Emergent Dichotomy

Simister and Younis, (1999) maintain that it is important to develop a rehabilitation sector that is affordable and sustainable, and also appropriate to the physical and social- political realities. The CBR philosophy, initially promoted as a way of providing access to rehabilitation within in primary healthcare systems, gradually changed both in its concept and content and is now orientated towards a more community development approach and the promotion of human rights (Ingstad 2001, p.786). Pupulin (1995) interprets this situation as an emergent dichotomy between medical and social models, i.e. bottom up models focused on community inclusion and empowerment and top down approaches focused on professional control generate a paradox that operates at practical and conceptual levels (Kendall et al 2000).

This dilemma also affects CBR workers if they have been trained in institutional settings (with an individual model of disability) for a community role (needing a social perspective of disability). Thomas and Thomas (2003) have observed a problem relating to the production of successful community programmes which relates to

training philosophies and practical emphases. They suggest that most CBR workers' courses have derived out of regular institutional courses. The curriculum in most instances is prepared based on the experience of the institutional instructors, who teach trainees to work in an institutional set up. They are loaded with technical skills training and lack the essential prerequisites to be successful in the community, namely, the ability to be innovative and to organise the families and the community for CBR work.

The present research allows for a comparison of these approaches as it includes community workers trained in two different settings. One approach known as Community Approaches to Handicap in Development (CAHD) taught in Bangladesh since 1997 is informed by a social model of disability and training and entirely community based rather than institute based.

The specific type of mid-level CBR worker trained is known as a Community Handicap Disability Resource Person (CHDRP). The preparation of these workers is a part of the overall CAHD strategy. These workers provide basic physical rehabilitation services in the community and referral services to secondary or tertiary care. However an important feature of the CAHD approach is its focus on the needs of the community as a whole rather than on the specific needs of an individual and the integration of impairment and disability issues into development assistance (Handicap International 2001).

A further feature is its strong emphasis on attitudinal change. This is achieved by working with key influential players in order to their change ideas and beliefs concerning disabled persons. The method operates at three distinct levels of the society and includes rigorous attempts to promote the rights of disabled people. The single training institute for CHDRP workers in Bangladesh is the Centre for Disability and Development (CDD) (See Appendix 3).

CHDRP workers interact with families and are home based. They are therefore directly exposed to issues around attitudinal change and exclusion of disabled people (Handicap international 2001).

They are employed only by the development organisations whose managers have first been given training on disability by CDD as a part of the strategy. Over five hundred

CHDRP workers had been trained by CDD by 2007 (Khan 2007) and the demand for courses was steadily growing. The development organisations become part of the wider body of organisations concerned with disability issues and having a collective political voice working at government level. In Bangladesh this is known as the National Forum of Organisations Working in Disability (NFOWD). As a strategy CAHD programmes demonstrate a capacity model challenging systematic practice to challenge disablist practices systematically by working at three societal levels. Two community projects participating in this study utilised CAHD as a strategy, namely the training institute, The Centre for Disability and Development (CDD) and a small micro-credit project Association of Development for Economic and Social Help (ADESH) whose staff included CHDRP personnel also participated (See Appendix 5).

A second group of CBR workers participated in this study were trained using an Institute Extension model (Thomas and Thomas 2003). The second group were known as Community Rehabilitation Technicians (CRT), were trained in an institute setting. This institute, The Centre for the Rehabilitation of the Paralyzed (CRP) has pioneered rehabilitation services for paralyzed people in Bangladesh and is the only institute in the country offering this specialised service. The CRT course lasted two years and approached disability mainly as an individual deficit problem although recent aspects of intervention indicated the course had elements of a wellness model e.g. including education on aspects of self-care to remain well. A considerable proportion of placement experience was institutional based before moving to work in the community.

The training emphasis for CRTs was focused mainly on treatment applications and technical skills as opposed to barrier removal although a small of loans could occasionally be provided through the parent institute. Supervision for trainee CRTs was provided by health professional staff and others. Additional experience was gained in established community projects linked to the parent institute. This course was underpinned by individual/medical explanations of disability and can be contrasted with the CBR worker role suggested in the ILO, UNESCO and WHO, (1994) definition of CBR, where disability is addressed as part of a general community development strategy. By including both CRT and CHDRP groups in this study a comparison of approaches to CBR can be i.e. of individual versus social model approaches, institute

versus community training and addressing disability as a health issue versus a developmental issue and employing a wellness versus capacity model framework.

3.3.2 CBR Training in Other Countries

The question of how to prepare mid-level rehabilitation workers for the community by addressing multiple barriers to inclusion (rather than a single focus on impairment and its effects) has produced comparable workers elsewhere. In South Africa, as part of the CBR programme, training of a new cadre of community workers known as Community Rehabilitation Facilitators (CRF) is now well established. The role of these workers is similar to the CHDRP role and was introduced and continues to run successfully at the Alexandra Health Centre and University clinic. The role focuses on assisting disabled people to overcome the multiple social consequences of their disability. The training of these workers includes not only at the medical knowledge but also an understanding of the social political and environmental factors in disability (Cornielje 1992).

The growing problem of provision of services to urban slum populations has been tackled in various ways through CBR. WHO's Disability and Rehabilitation Team (DAR), working with the Italian Association Amici di Raoul Follerau (AIFO) liaised with eight urban CBR slum projects periodically over three years and identified a number of helpful features that had helped to maximise opportunities for rehabilitation. These included development of resource centres using local facilities e.g. schools and training local volunteers (WHO/DAR 1995). Both these approaches have attempted to move away from an understanding of disability as a health issue, but still maintained theory around the need to attend to impairment as a health related issue with a provision of supportive medical assistance as a right. Thus they maintained the important parts of a medical knowledge base around impairment, but developed their theoretical base further to include and address discrimination and oppression by promoting equality, participation and social change. These training approaches illustrate the 'revitalisation of theory' where existing theory around traditional rehabilitation has been reworked to render it compatible with emancipatory practice (Thompson 2003).

3.3.3 Training that focuses on impairment

In Bangladesh a further two short training approaches have been focused around a single type of impairment, illustrating alternative local approaches to provision of

services in contexts of high levels of unaddressed need, and low levels of resource and personnel. They are the training of Developmental Therapists and Leprosy Physiotherapy Technicians. These approaches had already been successfully used in India prior to their introduction in Bangladesh, and their descriptions follow. They represent strategies to train and retain services in areas which are unpopular with professional physiotherapists. A careful situational analysis course indicated that social context was an important factor in designing the courses and setting objectives and that the selection of personnel to train was a key issue. Both approaches have produced workers who intervene in the lives of people and families affected by one type of impairment rather than the more generic training received by CBR workers. Courses are relatively short in duration compared to professional education, and levels of remuneration are lower. The rationale for these courses is described below.

3.3.4 Rationale for Training Developmental Therapists

Developmental therapy was first introduced into India by a British paediatric physiotherapist in 1987. Its introduction into Bangladesh came much later. Prior to the introduction of Developmental therapy training Carrington (2008) analysed work patterns in professionally qualified physiotherapists in Delhi which contributed to a marked lack of services for children with developmental problems. These included observations that qualified physiotherapists were being engaged by non-governmental or government institutes, or aspired to work in the US or the UK. A small number of expatriate physiotherapists were only temporarily available. As in many countries, paediatrics was not a popular field for professional therapists in India. Remuneration was poor and results came slowly. Retention of professional physiotherapists was also a problem at the National Institute treating children - The Spastics Society (Delhi) - but not simply because people were not interested. Other factors shaping choice included low salaries, few established posts in the government sector and the fact that the paediatric field did not lend itself well to private practice (Carrington 2008).

(Carrington 2008) reported that the main reason for developing the one-year Basic Developmental Therapy (BDT) course was to develop, and crucially retain, a knowledgeable workforce to address the therapeutic needs of children with developmental problems.

Because the high level of intensive training provided on the BDT course would go beyond the level imparted to professional physiotherapists in their undergraduate training, an additional three-month course in Advanced Paediatric Physiotherapy was also made available to interested qualified physiotherapists so that professional therapists as a group were not undermined. The title of the one-year formal course, 'Basic Developmental Therapy' (BDT) was intentionally generic to avoid any reference to Physiotherapy which might be a sensitive issue. Opportunities to build good relationships with professional therapists through discussion during general staff sessions alongside the formal course sessions were built into the programme.

The course in Delhi included skills with children but also a focus on families and on teaching skills, and required a readiness to work in urban slum areas and to supervise health workers in the already well-established rural projects. It also focused on inclusion issues as a sub-text exposing participants to the life context of service users. This was done by inviting input from parents, street families and from children and young people with impairments. BDT students became aware of children both with and without developmental problems. This inclusion demonstrated an important aspect of the course, namely an attempt to heighten an awareness of the lived experiences of these families, and to enhance social responsibility in course participants.

Teaching styles on the one-year course were varied in order to move gradually towards a more student-centred approach promoting confidence in enquiry, rather than dependence on retaining facts, a common learning style. An emphasis on an awareness of the social dimensions that many of these families faced, and strategies to address negative attitudinal issues, were an integral part of the course. A deliberate strategy was followed in the selection of candidates to ensure a skilled workforce that could be retained but who also exhibited appropriate attitudes towards families.

In 2008 the majority of those trained by Carrington as BDTs in India were continuing to work in this field, indicating sustainability. Some had developed projects and were emerging as strong agents of social change (a specific course strand) able to influence, energise and recruit others to work in a way which respects the rights of disabled people (Carrington 2008). However despite clear progress and achievements the status of the qualified developmental therapists when compared with Indian BSc degree

therapists remained low (Vohra 1999) and the Development Therapists were acutely aware of this.

Several issues addressed by Carrington in designing the course have relevance to this study, as it was developed in context considering gender and retention issues and social action in terms of providing access to habilitation services for children from disadvantaged groups. (This model was discussed in Chapter one Section 1.4.1). She also created a course which was of a relatively short duration (one year) and therefore more affordable, but also of high quality, and which gave students relevant community experience during the course. She considered that a further important aspect of the course was the relationship with other groups offering physiotherapy. All these issues have relevance to this study. Although Carrington did not use the term 'interactive model of disability', by acknowledging contextual factors in addition to impairment needs, e.g. barriers to access faced by poor families, the Indian Basic Developmental Therapy course appeared to approach disability as an interaction of individual and contextual factors and utilised both wellness and capacity practitioner models.

Retention issues around training personnel for paediatric therapy have also been identified elsewhere. Hinchcliffe, working in Jordan in the 1990s, found only selective interest in this field once physiotherapy students qualified, despite specific preparation during undergraduate studies. She concluded that in-depth training in developmental therapy should be reserved for those who expressed a genuine interest in working in this field, rather than imparted to all undergraduate students (Hinchcliffe 2005). She reported that this field was not seen to be strong in terms of career development or possible income source. It was also unpopular culturally with male students. However the female gender element exhibited in trainees made it more acceptable to recipient families.

Over the last fifteen years, informal courses in developmental therapy have taken place in Bangladesh, but a formally recognised course has only recently been approved by the Government. The potential benefits seen in instigating the course in Bangladesh was the provision of access to therapy including aspects of physiotherapy, speech and language therapy, and occupational therapy at low cost. Families were unlikely to have resources to access individual therapists and the employing organisations did not have

sufficient resources to provide high salaries to professionals who were in any case not readily available.

In Pakistan a similar gender-biased strategy was employed by Ogilvie (1989) in order to address the development needs of disabled children in the community. In Africa, Hinchcliffe, a British physiotherapist, recently introduced an intensive two-week physiotherapy course into Zambia and Malawi using volunteer Western therapists as instructors. This course specifically addresses the rehabilitation needs of families with children with Cerebral Palsy (Hinchcliffe 2008).

The strategies above all considered the recipient's context carefully and focused on outcome in terms of maximising benefit to disabled populations and their families through judicious use of training resources. The course in Bangladesh is not based on rights, however, but has a clinical and family focus.

3.3.5 Access to Physiotherapy for Persons Affected by Stigmatising Disease

In more stark social circumstances, leprosy physiotherapy technician training was introduced into India in the 1960s in order to address the significant levels of impairment in people with leprosy. Not only was work in this field unpopular but at the time of introduction people with leprosy were socially excluded, and access to both medical and physiotherapy interventions were minimal. The Leprosy Mission (TLM) adopted a strategy of specific training of Leprosy Physiotherapy Technicians in order to train and retain a workforce of physiotherapy technicians able to work only with this particular client group. The duration of training varies from weeks to several months.

The specific training in this one field is of a high standard at a medical level. Focusing on one type of impairment in detail has resulted in high levels of technical competency. However this narrow technical focus in training meant that the possibility of a wider role was not considered. There was little training given to directly address identity issues. The status of leprosy physiotherapy rehabilitation technicians has remained low compared to graduates from physiotherapy programmes (Watson 2007).

In Bangladesh the Leprosy Physiotherapy Technician training course was also an initiative of Leprosy Mission. Work in leprosy projects has not attracted the attention of qualified physiotherapists in Bangladesh, partly because of its rural location and the

comparatively poor remuneration it commands, compared to private work in city clinics and opportunities abroad. When leprosy physiotherapy technician training was first introduced into Bangladesh in 1991, professionally qualified physiotherapists were still unavailable. When they did qualify and became available, leprosy physiotherapy technician training was initially suspended since qualified physiotherapists were being offered training in leprosy and were being employed. However, despite receiving extra training in leprosy, physiotherapists could not be retained and therefore the training of Leprosy Physiotherapy Technicians was restarted (Bowers 2005). Courses have more male applicants than female but both are accepted.

While the worldwide strategy on leprosy to date originally focused on disease control, disability and stigma are the main concerns of people affected by leprosy, and leprosy workers have also been stigmatised by association (Withington 2006). Bangladesh made appreciable progress in the control of leprosy by achieving the WHO elimination goal by December 1998. However this was not uniformly achieved across the whole country. By the end of 2002 the prevalence was still above 1 per 10,000 in 15 areas (Withington 2006). These areas included the northern division of Bangladesh where the fieldwork was conducted for this part of the data collection.

The underpinning individual/biomedical model of disability on which leprosy physiotherapy technician training has previously been based, has not included specific attention to the negotiation of a positive identity nor imparted structural and cultural explanations of disability. The research will explore the results of this approach in terms of user perspective of interventions received, and the technicians' perceptions of their role in this field. The aspirations of both Leprosy Physiotherapy Technicians and Developmental Therapists are also of interest in this research.

It is worth noting that both Developmental Therapy and Leprosy Physiotherapy Technician trainings and the two mid-level CBR trainee courses CHDRP and CRTs are all independent courses with no pathways to higher academic attainment. A number of International Organisations such as the International Committee of the Red Cross (ICRC) working in areas of conflict have adopted an incremental modular approach locally to train physiotherapy assistants at the point of need. The ICRC has promoted such mid-level training as the only realistic way to meet population requirements. However, training is validated and gaining credits (via the European Credit Transfer

System) can count towards obtaining a degree, thus providing an additional career option. This has enabled the goal of providing professional services to be achieved.

Handicap International (HI), working in the refugee camps on the border between Cambodia and Thailand developed a HI certificated, intermediate-level modular training programme in physical therapy to rapidly address urgent needs for basic functional rehabilitation provision. The decision was taken in order to meet the needs of disabled people with respect to their rights later defined in the Convention on the Rights of Persons with Disabilities, (Articles 19, 20, 25 & 26) and in accordance with HI's own methods and approaches. However during the same period HI also opened a three year diploma course in Phnom Penh. Thus, both HI and ICRC have utilised intermediate and professional training strategies concurrently.

In contrast WCPT maintains that in geographical areas facing a critical shortage of health professionals efforts should be made and supported to increase professional training opportunities (undergraduate and graduate), and to provide incentives for the retention of health professionals. In a Joint Positional Statement together with other health professional groups they state that in their view whatever the strategy selected, the idea of 'task-shifting', when roles by qualified professionals are fulfilled by non-professionals such as assistants, should not replace the development of sustainable, fully functioning healthcare systems, 'It is not the answer to ensuring comprehensive care, including secondary care, is accessible to all' (Adapt 2008). It is notable that WCPT aims to protect the interests of its professional members whereas ICRC and HI are concerned primarily with the needs of disadvantaged groups.

3.3.6 Summary

A careful situational analysis has influenced decisions around the preparation of personnel to engage in the field of disability in developing contexts. Community-based rehabilitation was introduced in order to increase accessibility to rehabilitation services and has now developed into a rights-based model of practice underpinned by a social model of disability. Various types of mid-level CBR worker training have emerged. These tend to reflect the philosophy and emphases of their training institute and can be divided into two groups, namely approaches based on a social model of disability and those based on an individual perspective of disability. The first group

approach disability as a developmental issue, in this study the training produces home-based workers concerned with both impairment needs and community attitudinal change. The second group utilises an institute extension model. Workers in the project studied mainly prioritise interventions around impairment in preference to community involvement. Including examples of both approaches in the research will allow a comparison of their impact.

Other approaches to the provision of personnel include training of workers around specific impairment-related needs. Developmental Therapy training and Leprosy Physiotherapy Technician training were both introduced in Bangladesh in order to train and retain personnel in situations of limited resource. These enable people with specific impairments to access therapeutic services at low cost. A rationale for both approaches has been presented. The practitioner models and underpinning models of disability informing the four alternative approaches to intervention are shown in the table below.

Table 3.4 : Alternative training approaches to intervention in disability

Type of Worker	Underpinning model of disability	Model
CHDRP	Social	Capacity
CRT	Individual	Wellness
Development therapists (As practiced in Delhi, India)	Interactive (An interaction of individual and contextual factors)	Wellness /Capacity
Leprosy Physiotherapy Technician	Individual	Wellness

3.3.7 Chapter Three Conclusion

The main challenge to professional education and various training approaches is to produce services which are appropriate to the health and social context of the country. Professional physiotherapy education in Bangladesh has been influenced in its development by a number of models of disability. Historically, professional education in minority settings has been underpinned by an individual model of disability and marked by professional control. It has been argued that, together with volunteers, these concepts have been imported into Bangladesh. However, many aspects of professional education in minority settings such as the UK may not be appropriate for developing contexts. Other approaches to disability in developing context informed by

a social model perspective have proposed community-based rehabilitation as a more appropriate approach to rehabilitation in developing contexts. This approach prioritises community ownership, challenges discrimination and exclusion of disabled people promoting empowerment, and requires a rights-based approach. However when CBR workers are trained in medical institutes which espouse an individual model of disability, the roles adopted by of CBR workers often reflect this.

In situations of low resources, and where access to therapeutic services is limited, other approaches focusing on training workers to address the needs of people with a single type of impairment have also emerged. These different approaches to training and professional education present an educational dilemma. Design of research to investigate their strengths and weaknesses in Bangladesh based on service user perspectives is the topic of the next chapter.

Chapter Four

4. RESEARCH METHODOLOGY

4.0 Introduction

The purpose of this chapter is to describe the way in which the methodological decisions were made and give a comprehensive account of how the research strategy was chosen and implemented. The chapter is divided into six sections.

Section one introduces the nature of the research inquiry. This is related to the global interest in evidence-based practice, sources of evidence and definitions of service quality. Ontological and epistemological considerations which led to the choice of a naturalist paradigm are described. The position of the researcher as a research instrument is acknowledged. Section two identifies the research questions and locates the research inquiry in a qualitative methodology. Choice of methods of data generation and the topic guide development is discussed. Section three explains how decisions were made around the recruitment of user participants including sampling strategy, the use of networking to obtain a user sample and acknowledgements of participants. The particular challenges of obtaining data from this population are discussed. Section four explains how decisions were made around recruiting participants for focus groups and individual interviews from the different groups of providers. Section five describes the process for data analysis and identifies ethical issues in the research. Considerations around the generalisability of the study are then addressed. Section six presents a reflexive account of the researcher as a research instrument. Consideration is given to the impact on the study of the researcher working in a second language and issues in translation. A conclusion is then drawn.

4.1 Section One

4.1.1 The Nature of the Research Inquiry

In the previous chapter it was argued that emergent approaches to training and educating personnel around disability in Bangladesh have been influenced by various international priorities and emphases and by developments in thinking around approaches to disability. The different ways of thinking about disability have been

theorised using different 'models' of disability discussed in chapter one. Professions such as physiotherapy are challenged to respond appropriately to changes occurring in approaches to disability worldwide and changing contexts of practice. Higgs and Edwards (1999) maintain that in order to address these challenges they need to be identified and understood. Different practitioner models have been proposed in a bid to find suitable practitioner models for today and the future. Some of these were discussed previously in chapter three (Sections 3.1.4 and 3.1.5). A number of alternative approaches to the provision of health and rehabilitation services in the world's poorest countries have also emerged. These include the training of mid-level community based rehabilitation workers (Section 3.3.1) and other initiatives where workers have been trained to address the needs of people affected by one type of impairment (Section 3.3.3 –Section 3.3.5).

A global trend in healthcare is the call for evidence-based practice (Higgs and Hunt 1999, p.14). Evidence-based practice has been promoted as a model for physiotherapy practice (Gibson and Martin 2003) and supports the importance of establishing interventions that are informed by dependable theory. The word 'evidence' is rooted in the concept of experience, relating to what is manifest and obvious (Upshur 2001). Evidence can be considered to be knowledge, derived from a range of sources. Exactly what counts as evidence becomes an important consideration. Rycroft-Malone et al (2004) maintain that knowledge in healthcare can be generated from four types of evidence named according to the source of knowledge i.e. research, clinical experience, patients, clients and carers and the local context and the environment. Each of these sources provides us with types of knowledge. Two types of knowledge were discussed in chapter three (Section 3.1.3), namely propositional knowledge, drawn from research and scholarship and non-propositional knowledge, drawn from personal knowledge and professional craft knowledge. It was emphasised that non-propositional knowledge should not be underestimated and can drive new knowledge in a health profession. A further important source of non-propositional knowledge is also available, namely, knowledge drawn from the local context and environment. This knowledge, derived from the experiences of disabled people whose lives are embedded in the culture and social structures, constitutes a rich source of evidence which can inform education for the delivery of evidence-based healthcare. This

research will draw on non-propositional knowledge from both practitioners and from the local context and environment. Stetler (2003) has described this evidence source as 'internal evidence' and it is argued that such evidence has the potential to inform education around the development of evidence-based practice.

The decision to engage with disabled people within their contexts and seek 'insider' perspectives of both the experience of disability and interventions received from personnel engaging in this field was chosen so that emerging evidence would be both dependable and consistent with 'client-centred' ideals. Sound clinical practice demands a strong theoretical base but theory developed in the absence of clients' perspectives provides an unstable base from which to inform client-centred practice (Hammell and Carpenter 2004, p.24). This notion is linked to definitions of service quality which often is discussed in terms of 'satisfying customer requirements' and 'fitness for purpose'.

Most definitions of service quality use the words 'perceived service quality' to emphasise that it is service quality from the customers' perspective (Cuganese et al 1997). Indeed Davidson et al (1997) demonstrated that service delivery can be effective only if it is addressing the problems perceived by service users. Gronroos (1984) and Parasuraman et al (1994) refer to comparisons, which consumers make to discuss service quality, between expectations of service and perceptions of actual performance. Despite the importance of this topic, little has occurred in Bangladesh in terms of assessing perspectives of users around disability services currently available, and the study seeks in some ways to address this.

Such locally available data can have a key role in providing evidence on which to base client-centred care. Client-centred rhetoric espoused in today's professional practice now demands that outcome assessment reflects the values, priorities and goals of the client rather than those of the therapists. It is significant that a lack of agreement between clients and professionals in several areas has often been noted. These include their preferred approaches to service delivery, the expectations of clients, priorities of treatment goals and presenting problems (Hammell 2004, p.67). Clients have been shown not to share the same priorities, preoccupations or perceptions of problems as their healthcare providers (Clark, Scott and Krupa 1993). This points to a need to examine the extent to which exogenous influences on professional and other

healthcare worker courses influence delivery of interventions compared with endogenous influences encountered as a part of role socialisation.

Research studies in the West have confirmed the effectiveness of including 'client' input in service evaluation. Corring (1999, p.8) writes 'Several studies of client involvement in service have demonstrated that clients are capable of determining what services they find most satisfying and that such involvement can lead to better health outcomes'. Satisfying the interests of all stakeholders in provision of services is an important consideration. The consideration of all stakeholders interests points to the need to assess to what extent workers and professionals interests are being addressed in and through courses offered. Inquiry around the personal development needs perceived by the different groups has therefore also been incorporated into the research inquiry as a secondary concern.

In summary, theory and practice play an important part in the preparation of healthcare practitioners (Eraut 1998). Ways in which practitioners intervene is influenced in part by the way in which disability is understood and socialisation experiences during training. The particular interest of the study is to engage with evidence from both users and practitioners to establish what is happening in practice and draw out evidence, which is of potential use in informing professional physiotherapy and related healthcare worker interventions within this context.

The timeliness of the research relates to the fact that initiatives to introduce services such as physiotherapy in Bangladesh are relatively recent and the number of personnel trained is comparatively small compared to the numbers of potential beneficiaries. This situation suggests that an investigation of ways in which disability is experienced in Bangladesh and the perspectives of service users around interventions they have received from provider groups can be used to inform the various educational initiatives whilst they are still at a very early phase of development.

4.1.2 Ontological and Epistemological Considerations

The way a researcher approaches a topic for investigation is based on an ideological framework (ontology) which indicates ways of knowing about the world (epistemology) that are then implemented in particular ways (methods). Lincoln and Guba (1989, p.37) present four alternative ontological stances:

- 1 Naïve realism - asserts that 'the world in which we have knowledge exists independently of our knowledge of it', hence there are tangible 'truths' in the social world and research aims to reveal this truth.
- 2 Perceived reality - there is one reality but this cannot be known fully, only appreciated from particular perspectives or perceptions.
- 3 Constructed reality - where reality is constructed by individuals. There are an infinite number of constructions and an infinite number of realities.
- 4 Created reality - there is no reality at all; rather, the universe is brought into being by the participation of those who participate.

This research was concerned with beliefs, values and expectations of two groups of people, disabled people and individuals offering services involving physiotherapy. Every individual has different experiences, and also experience similar things differently. It therefore sought to construct a time and context specific reading of events and meanings given to events from the data collected from the participants. It was premised on the belief that there are no universal experiences or truths waiting to be uncovered. Participants were guided to discuss beliefs and experiences they may not have considered before. Interviews were audio-taped and this constituted data. Outcomes were finally produced by deconstructing and reconstructing events and meanings attributed to them. The aim was to increase understanding of the perceived realities. This stance fits with Lincoln and Guba's third ontological stance, that of a socially constructed reality.

Secondly, the research did not assume a single objective reality, or truth, waiting to be uncovered. It could be considered therefore to fit into a naturalistic paradigm, rather than a positivist paradigm (See Table 4.1 below). Moreover, it was likely that multiple realities were constructed jointly by the researcher working with an assistant and the participants and hence the researcher, or 'knower', could not be separated from the knowledge created, or 'known'. As a result, the knowledge was dependent on the context and the time of its construction and cannot be generalised in its entirety. (See Table 4.1)

Table 4.1 : Contrasting positivist and naturalist axioms (Lincoln and Guba 1985, p.37)

About	Positivist paradigm	Naturalist paradigm
Nature of reality	Reality is single, tangible and fragmental	Realities are multiple, constructed and holistic
Relationship of knower to known	Knower and known are independent	Knower and known are inseparable and interactive
Possibility of generalisation	Time and context-free generalisations are possible	Only time and context bound working hypotheses are possible
Possibility of causal linkages	There are real causes before or simultaneous with effects	All entities are in a state of mutual simultaneous shaping and so cause and effects are indistinguishable
Role of values	Inquiry is value free	Inquiry is value bound

4.1.3 The Position of the Researcher as a Research Instrument

The epistemological position of the researcher relates to theories of knowledge, and is concerned with the principles and rules by which social phenomena can be known and how knowledge can be generated (Mason 2002). Different epistemologies have different things to say about how social phenomena can be known and the epistemological position of the researcher needs to be consistent with their ontological position. In this study, the position of the main researcher was that of a 'research instrument' in the data production. This can be illustrated by the metaphor of a 'traveller' suggested by Kvale (1996):

A traveller is on a journey with a participant. The traveller, representing the researcher prompts the participant to share their story. This is interpreted by the traveller. The traveller guides the participant into new insights as he considers the story and reflects these back to the traveller. Without this influence, these insights would not exist. This process is ongoing. The final destination of the journey or knowledge produced is dependent on both contributions. The traveller's influence cannot be removed from the data collected. The researcher is thus recognised as an instrument in the data production.

(Adapted from Kvale 1996)

This position necessitates an on-going reflexive evaluation of my own impact, as a researcher, on the research findings. It calls for a rejection of the position proposed by Rubin and Rubin (1995), who suggested that researchers should maintain an objective and neutral viewpoint and avoid disclosing information about themselves. Reflexivity refers to the conscious examination of the position of the researcher within the research. It is recognised that the biographical position of the researcher will affect the

research relationship and the nature of the data collected (Carpenter and Hammell 2000). A reflexive account of the researcher as a research instrument is therefore presented in section six of this chapter.

4.2 Section Two

4.2.1 The Research Questions

Three main research questions were formulated. Evidence generated by researching the first two questions was intended to inform the third question. The research questions are as follows:

1. What knowledge, beliefs and expectations around disability typify users of therapeutic services in Bangladesh?

This question was subdivided into three questions:

- 1a** How do disabled people or parents of disabled children perceive their experience?
- 1b** What perspectives do recipients of interventions hold around the interventions made by physiotherapists or related healthcare workers?
- 1c** What wider expectations do recipients have with respect to society's responsibility to them?

This question was formulated to find out what it is like to be a disabled person in Bangladesh and to understand how disabled people feel about the interventions they have received from different providers of physiotherapy and what they expect from their society as a whole.

The second research question was:

2. What beliefs do student physiotherapists and related healthcare workers hold around the needs of disabled people and their own particular role in providing intervention, and, what is influencing this perception?

This question was subdivided into three questions:

- 2a** What perceptions do the students and others hold around the needs of disabled people?
- 2b** What roles do they adopt with disabled people?

2c What personal development needs do these workers have?

This question aimed to identify perceptions held by the different types of worker around the nature of disability and their particular role in meeting the needs of disabled people. The question aimed to elicit an understanding of influences upon role perception. Personal development needs were of interest as a secondary but important concern as these also illustrated roles that groups envisaged for themselves as service providers.

The third research question was informed by the previous two:

3. Are there identifiable adjustments in professional education and training of related healthcare workers around disability that might be beneficial for disabled people in this social context?

This question was evaluative, designed to stimulate thinking about the strengths and weaknesses of the courses in preparing different groups of workers for their roles when considered against the backdrop of user perspectives. It was included in order that composite usable knowledge emerging from both groups might be made use of in ways that produced meaningful outcomes for disabled people. Oliver (1996, p.141) highlighted the need to make disability research more relevant to the lives of disabled people and more influential in improving their material circumstances. Although the research does not claim to follow an emancipatory paradigm, in that disabled people were not directly involved in setting the agenda for the research, the findings can nevertheless assist in the development process as an additional resource for professional physiotherapy education and training of personnel for this field.

All courses identified in this study produce workers who deliver physiotherapy as a significant part of their role with disabled people. In addition to the delivery of physiotherapy, students and workers completing these courses are united by a common need to understand the experience of disability in Bangladesh. Ellis (1993, p.19) has suggested that inadequate responses to the needs of disabled people 'results as much from a failure of imagination as from a shortage of resources'. If evidence of inadequacy does emerge as a finding, this may relate to a need for courses to be better informed by evidence about disability emanating from within this context. Such evidence may stimulate imagination to identify more adequate responses. The third

question facilitates a consideration of how direct evidence from service users can be utilised to inform education around disability so that courses and interventions align maximally with perceived needs of service users.

4.2.2 Locating the Study in Qualitative Methodology

The decision around methodology relates to the question of which research approach/methodology best allows the subject of interest to be explored. Mason (2002, p.1) claims that qualitative research has an unrivalled capacity to constitute compelling arguments about how things work in particular contexts. Because this study related to a specific context, consideration was given from the outset to locating it within a qualitative methodology. Qualitative enquiry is grounded in a philosophical position which is broadly 'interpretivist' in the sense that it is concerned with how the social world is interpreted, understood, experienced, produced or constituted (Mason 2002, p.3). Because the study sought to explore the social world from participants' perspectives rather than from the researcher's, it was therefore well matched to qualitative study. This approach is described as an 'emic' or insider approach, in contrast to an 'etic' or outsider approach, where research is conducted 'on' participants in order to test a hypothesis empirically. Robson (2002) suggests that an emic approach is particularly useful when working with a marginalised or excluded group as it gives participants a 'voice'. The marginal place held by disabled people in Bangladeshi society has been previously discussed (Sections 2.2.1 and 2.2.2) and this consideration alongside others confirmed the need to adopt qualitative methodology.

Qualitative research methods are being increasingly reported in literature and are contributing unique evidence upon which to base rehabilitation practice (Carpenter 2004, p10). Carpenter (2004) maintains that qualitative methods can be used in a number of ways, for example, to justify decisions and explore issues in service provision, and to facilitate the development of theory. As this research is ultimately concerned with the effectiveness of service provision then it is well suited to a qualitative approach. One of the main reasons Mason (2002) gives for the importance of qualitative research is that 'through qualitative research we can explore a wide variety of dimensions of the social world, including the texture and weave of everyday life, the understandings, experiences and imaginations of our participants, the ways that institutions, discourses or relationships work and the significance of meanings

they generate' (Mason 2002, p.1). As one of the main interests of this research was to pursue an understanding of the impact of context on perspectives of users then a qualitative approach was appropriate to choose. The research was also concerned with the accounts of students and healthcare workers around the interpretation of their role with disabled people. Blaikie (2000, p.234) maintains that the qualitative interview, particularly the in-depth variety, can get close to social actors' meanings, interpretations and accounts of the social interaction in which they have been involved. The potential of the qualitative interview to address the research questions was a further reason for the choice of a qualitative methodology.

In order to generate new theory and new explanations qualitative research uses two underlying logics of explanation, inductive and deductive. Induction is the generation and justification of general explanation based on the accumulation of lots of particular but similar circumstances. Deduction moves in the opposite direction, from a general statement to explain a situation (Gibbs 2007).

Rather than starting with theories and concepts that are to be tested, inductive logic in qualitative research favours their generation in tandem with data collection in an iterative fashion. The research was concerned with generating explanations within a particular context. A methodology which used the logic of induction was appropriate to use in this circumstance, as it did not explicitly set out to 'test hypotheses'. However, it is important to note that the research did not start from a blank sheet completely, ideas emerging from theoretical chapters and from previous personal experiences working in Bangladesh served to guide and frame the analysis.

4.2.3 Methods of Generating Qualitative Data

The term 'qualitative methods' is an umbrella term encompassing a range of approaches and strategies for collecting, analysing and interpreting data. A number of qualitative methods can be employed to generate data. Qualitative data may be collected by use of in-depth interviewing with individuals or groups (focus groups), through observation with or without the participation of the observer, by keeping field notes, by means of open-ended survey questions, or from action research where data sources are multiple and complex (Malterud 2001). Gibson and Martin (2003) provide

an overview of research questions and qualitative approaches shown in the table below.

Table 4.2 : Research questions and qualitative approaches.

Taken from Gibson and Martin (2003)

Research question	Qualitative approach	Common methods
What is the meaning attached to this phenomenon?	Phenomenology	In depth interviews Analysis of personal writings
What is life like for this group?	Ethnography (Anthropology)	Participant observation Formal and informal interviews Video or photographic analysis
What is happening? Why is it happening?	Grounded theory (Sociology)	In-depth interviews Focus groups
What are they communicating? How are they communicating?	Discourse analysis Sociology, linguistics	Document analysis

The study was based upon two major ‘What?’ questions and a further question around application. The first two questions constituted an intellectual puzzle exploring the social realities of both disabled people and physiotherapy providers in Bangladesh. Based on a consideration of optional methods to consider, individual semi-structured, in-depth interviews were chosen as the method of choice for data collection with all ‘users’ in the study. This was chosen to allow individuals space and time to explore their experiences through discussion, and was preferable to other variations in qualitative interviewing, particularly in a context with a strong oral tradition and high levels of illiteracy.

The semi-structured nature of the discussion enabled a relatively informal face-to-face interaction to occur, rather than a formal or more rigid question and answer format, which may not allow topics of importance to users to be raised and explored. Burgess (1984, p.102) describes these as ‘conversations with a purpose’. Primary data in this research was obtained from individual users in semi-natural settings, when they were not actually engaged in the activities of interest. These settings were, for users, in or near their own homes or in clinics - settings with which they were familiar.

Charmaz (2002, p.16) suggests that in gathering rich data, everything that is learnt in research settings or about a research topic can serve as data. Based on the premise that observations, which were contextual and situated revealed data in multi-dimensional ways, these were recorded as part of the fieldwork and added to the

richness of the data. The study fit into a naturalistic paradigm in which the researcher was conceptualised as being active and reflexive in the research process. My own experience from a vantage position as an experienced clinician with previous experience in Bangladesh and reasonable language fluency, meant that observations of any interactions occurring between users and providers on field visits were especially valuable and added to the richness of the data. It was inevitable that observations would be influenced by my own background and this inability to be a 'detached witness' is acknowledged in the reflexive account given.

For students and other workers, settings were classrooms or places of work. Semi-structured interviews alone were chosen as a method to generate data with related healthcare workers who had completed short courses and were working in the field. It was anticipated that numbers of physiotherapy-related healthcare workers in any organisation would be small and workers would be employed in a number of locations. This meant that requesting interviews in work venues would possibly be easier for organisations to accommodate.

Documents and information relating to education and training of the different provider groups were also collected and added to the background information of the different groups. For students on lengthy professional courses semi-structured interviews were combined with focus groups for important reasons. The more conservative female students were often reluctant to speak in mixed gender student groups, but would express their opinions elegantly in one-to-one conversations or in single gender groups. By providing an interview option, female students were given the opportunity to participate in a setting in which they would feel comfortable. In addition, this option gave both male and female individuals, who might hold ideas strongly at variance with group members, an opportunity to express these without any fear of repercussion from the group.

Female students were outnumbered by male on all professional courses, and single gender groups were considered but, as it was not known how many female students would be willing to participate, mixed gender groups increased the chance that the group would be large enough to hold a discussion and have a spectrum of views represented.

The goal in working with students on the lengthier professional courses was to capture something of professional socialisation experiences occurring on these courses. Kreuger (1998, p.18) described the focus group as 'a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment'. Millward (1995) highlights further advantages in the discussion process itself:

'Focus groups are communication events in which the interplay of the personal and the social can be systematically explored... The assumption...is that people will become more aware of their own perspective when confronted with active disagreement and be prompted to analyse their views more intensely than during an individual interview.' (Millward 1995, p.277).

Focus group discussion allowed for wider group dynamics to influence the data. Typically, focus groups involve around six to eight people who meet once for a period of an hour and a half to two hours. Groups consisted of either first or final year students. The discussions were scheduled to last for one hour followed by refreshments, in order to fit in with other commitments students may have.

Different phases in the group discussion process are recognised i.e. forming, storming, norming and adjourning (Tuckman and Jensen 1977). It was anticipated that because year groups would be familiar with each other, and have the same levels of experience the 'forming' phase of the group process would be fairly straightforward allowing discussion to progress smoothly onto the 'storming' phase and then continue into 'norming', and 'performing' stages before moving towards closure in the 'adjourning' stage. In the adjourning phase participants would be thanked, assurance of their confidentiality would be reiterated and then the recording would be switched off. It was noticeable that over the refreshments which followed, discussion often returned to topics discussed previously. Only at this point did some participants express critical opinions about aspects of their experience, even though at the start of the discussion, the option of turning off the tape at any point to allow for sensitive discussion had been given. This was unsurprising as expectations that authority figures should be shown respect made it particularly difficult to be openly critical. A recording of this in the wrong hands could create potential difficulties. Tapes were routinely removed from the tape recorder at the end of interviews, and this proved to be a sensible precaution as the recorder was stolen on one journey and had to be replaced.

Transcripts of the interviews produced by the research assistant were kept in the possession of the main researcher along with the tapes.

Although the participant numbers in the focus groups was set between six and ten, the actual group sizes ranged between five and eleven. I felt that both the slightly smaller and larger group numbers were acceptable. All participating training institutes were known to teach in mixed group settings and therefore this would also be a natural forum for student participation and would allow opportunities for gendered debate to emerge around the topics discussed.

4.2.4 The Development of Topic Guides

All interviews and focus groups utilised topic guides prepared beforehand. These consisted of a loose plan of topics to be explored. The guides were devised jointly by the researcher and the assistant. The topics listed were derived from a number of sources. These included ideas which related to the research questions and were gained from reading the literature, discussions with my first supervisor, experiences of living and working in Bangladesh, and other areas of relevance suggested by the assistant. They acted as aide-memoires. Modifications to the guides were made as the interviews and focus groups progressed, and further areas of interest emerged. The topic guides are shown in Appendix 6.

The same topics were discussed in interviews and focus groups and with both first and final year students. An opportunity was given to all groups to discuss personal development needs. The topic guides were utilised slightly differently with the various groups. They were, for example, and modified with first year students for whom 'significant experiences on clinical placements' could not be discussed. For both males and females, gendered aspects of their role were discussed. This inclusion was based on observations around gender stratification in almost all work activities.

4.3 Section Three

4.3.1 Developing a Sampling Strategy

The research was based on a naturalist paradigm and located the inquiry in a qualitative methodology grounded in a philosophical position, which is broadly 'interpretivist'. It adopted an ontological stance of a socially constructed reality and utilised data generation methods, which included the interviews and focus groups in

the fieldwork. Having decided a research strategy and design it was necessary to identify the potential research population and decide upon a sampling strategy and selection and procedures to identify, choose and gain access to relevant data sources.

Qualitative research uses non- probability sampling for selecting the population for study where units are selected to represent particular groups within the sampled population (Ritchie and Lewis 2003). Purposive sampling is criterion-based (Mason 2002) where decisions are often made in the early design stages about which criteria are used for selection and informed by a range of factors including the principal aim of the study.

There were two distinct target populations in this research. The first target population was made up of disabled users who had received interventions in the previous year from each of six provider groups. The provision of physiotherapy was a significant part of the service received from each provider group. The purpose was to capture a spectrum of perspectives around the experience of disability from disabled users including their perceptions around the interventions they had received and their expectations from the society generally. A target of thirty user interviews in semi-natural settings was based on what was feasible to aim for given the constraints on time, finance, co-operation from different institutes and other work commitments of the researcher. The aim was to give 'equal voice' to each of the user subgroups by including five service users for each type of provider. Thirty interviews would also enable both commonalities across the total user group and collective identities user sub-groups to emerge. Table 4.3 shows the plan for user interviews. For context, It also indicates the total numbers of practitioners available.

Table 4.3 : Plan for user interviews

Identity of practitioner seen	Planned number of participants	Total numbers in 2004 (approx.)
Developmental therapists	5	20
Leprosy physiotherapy technicians	5	30
CHDRP community workers	5	300
CRT community workers	5	20
Diploma level PT	5	50 trainees 10 qualified
BSc Level PT	5	380 trainees 150 qualified

4.3.2 Criteria for User Selection

The inclusion criteria were deliberately kept to a minimum to reduce demands on organisations that had agreed to provide access to users. All participants needed to have received intervention within a period of one year prior to the interview from any member of the provider groups of interest. However because the intention was to cover a diversity of experience, the sample frame needed to include a wide age range, both male and female participants, a variety of levels of impairment and different socio-economic levels. The goal in purposive or criterion sampling is to ensure that the diversity needed is represented and therefore I needed to monitor recruitment in order to achieve this.

I was heavily dependent on co-operation from different organisations particularly those in distant locations. The users treated by professional groups were more local. Because of this I was able to ensure the sample covered the relevant characteristics early on in the recruitment process by requesting this information from the recruiters before a decision was made. The recruiters were all physiotherapy staff known to me who agreed to help recruit participants known to have received interventions within the preceding year. Different participants represented different combinations of characteristics, and as the recruitment proceeded all the essential characteristics were covered. In more distant locations, although I specified the diversity needed, I had little direct control over recruitment. In these locations directors of participating organisations assumed responsibility to recruit participants and arrange the interviews.

Parents or guardians were to be interviewed for children less than 16 years old. If an adult user had an impairment that affected communication, such as stroke, the main carer was invited to speak on his/her behalf. Attempts were made, however, to include and capture the views of users themselves wherever possible.

I had previously noted in every hospital and clinic setting for adults I had encountered that wards for male patients out-numbered those for female patients. I therefore felt it was important not to diminish evidence of possible privileges in access relating to gender bias. Where possible, user interviews were held before provider interviews in order to establish the 'user voice' as a priority and inform my own thinking about topics to be discussed with providers. However, there was a small degree of overlap in

the later stages of the interviews where both users and professionals were interviewed on the same day, in accordance with arrangements made by participating institutes.

4.3.3 Pilot Interview for User Group

Before the main data collection began, a pilot interview was conducted in the home of one of the female users who had been seen by one of the newly qualified BSc students. This was necessary to test whether the methods adopted were appropriate ways in which to answer the research questions. The pilot enabled consideration of the questions themselves and led to a modification of the topic guide. Decisions on spatial positioning of persons and equipment were reviewed and the roles of the main researcher and assistant were clarified. Arrangements for transcript production and joint reviews were also made after the pilot interview. This exercise was also extremely useful as the electricity supply was suddenly interrupted in the middle of the interview, halting the recording. This experience led to the purchase of compact new equipment and a generous supply of batteries. A further outcome was a discussion with the assistant on how each stage of the interview would proceed. Following the pilot, a definite plan for user interviews was drawn up. This was systematically followed over the following weeks and months as users who fulfilled the required criteria were gradually recruited.

4.3.4 Acknowledging User Participants

Decisions around acknowledgement were made after discussion with the Bangladeshi research assistant and others around an appropriate and acceptable token of thanks. All the user participants were given a shawl at the end of the interview. However when the weather became much hotter, this was replaced by its monetary value of 500 taka (approximately £5 sterling), with which they could purchase a small item of their choice. All student groups and individual student interviewees were offered light refreshments after the interview and no other token of thanks. It was explained to all participants that, although the research would deliver little direct benefit for them as individuals, it was anticipated that the outcome of the research would benefit the wider disabled community.

4.3.5 Users Seen by Leprosy Technicians and Developmental Therapists

The population of Leprosy Physiotherapy Technicians trained and working in Bangladesh at the time of the research was around thirty workers based on numbers supplied by the American expatriate working in the physiotherapy department. Five user interviews were arranged at a rural leprosy field clinic in a district in northern Bangladesh. (See Appendix 7 for details of this project). Permission for these interviews was initially sought from the National Leprosy Mission Director in the capital city, an expatriate. Arrangements were then made using e-mail communication with the local Bangladeshi project director. The choice of location in a rural project was deliberate in order to locate interviews close to the local community in which participants lived. The field project chosen had links with hospital-based services further north and was in regular communication with them.

The director of the field work delegated responsibility for user recruitment to the staff member in charge of the rural clinic. He was asked to identify five participants who had consented to participate in the study. The inclusion criteria stated here, as elsewhere, was simply that all participants should have been treated by a leprosy physiotherapy technician within one year prior to the interview date. Further selection criteria around individual participants were deliberately not specified. Although delegating the selection introduced a possibility of bias, by allowing users to be selected who would only give a positive report, asking local staff to be in control over the choice of users would make recruitment as easy as possible for them to arrange and would reduce any sense of scrutiny that the prospect of these interviews might engender in staff. This arrangement was also made for practical reasons. The journey involved was a five-hour overnight bus journey and the location meant that there was little opportunity to have a more direct influence on participant selection.

In the event it appeared that little, if any, prior discussion with any potential users had taken place before I arrived. Users appeared to be invited to take part on the spot by the nominated staff member as they arrived at the clinic to be seen. I watched as they disembarked from rickshaws outside the clinic and walked towards a small cement building located in a clearing just off the main road through the village. As they entered, they were approached by the staff member who spoke to them and directed them to the rear of the building. This member of staff then arranged for a small table

and chairs to be placed in the open air at the back of the clinic. The close proximity of the chairs to an open window meant that their interviews could be heard by people inside the building. In order to expose gender bias in the selection process, a gender ratio was not specified. This allowed a naturally occurring selection of users to be recruited. Four male and one female were recruited sequentially as they arrived.

The second group of users to be interviewed were all parents or guardians of disabled children and had been seen by developmental therapists at one of two locations. Based on numbers supplied by one of the developmental therapists interviewed, around twenty developmental therapists had been informally trained in Bangladesh at the time of the research. Only three of the five user interviews arranged were conducted because in one location the school director had blocked two interviews with parents. This first interview took place in Kalyani Special School for Disabled children in Dhaka. Two subsequent interviews were located in a Treatment and Assessment Unit in a the National Children's Hospital; Shishu Bikash Clinic. (For details of both organisations, see Appendix 8 - Bangladesh Protibhondi Foundation). This second interview location was a Child Assessment and Treatment Unit in a large Government Children's Hospital in the capital city. Both interviews here were arranged by the daughter of the retired founder of the first organisation, who was happy to participate. She offered strong support for the research and offered herself for a recorded interview.

During the course of making the arrangements in the first location, the importance of observing formalities in Bangladeshi culture was strongly impressed upon me. I had obtained permission to go ahead from the recently retired founder of the school and followed her instruction to liaise directly with teachers to arrange recruitment of both therapists and users. On arrival for the first user interview at the school in Dhaka, I was ordered to go immediately to the director's office by the guard. There I was sharply reprimanded by the newly appointed director. She stated that, as she had not been fully informed about my proposals she was not granting her permission for my visit. I was then questioned at length on my knowledge of research principles and about the university department to which I was attached. She appeared to be satisfied with the answers given and having received an apology from me, she then said that she would allow me to proceed with an interview with one of the teachers who was also the

parent of one of the children in the school. The incident served as a timely reminder of the sensitivity around status and information and impressed upon me the importance of adhering to formalities in Bangladeshi culture and of following what was commonly referred to as 'the chain of command'.

4.3.6 Users Seen by Community Based Rehabilitation Workers

The next group of five users recruited had been seen in the previous year by one type of CBR worker known as Community Handicap and Disability Resource Persons (CHDRP). The project approached was in Savar, approximately 40 miles outside of the capital city. This was one of two projects suggested by a senior female disabled member of staff working for the organisation training CHDRP workers. The project was primarily involved with micro-credit. The organisation was relatively easy to travel to and agreed to participate.

Permission for the interviews was first obtained from the director of the organisation known as Association of Development for Economic and Social Help (ADESH). Choice of participants was again delegated to workers in the project for the same reasons noted above. (Information about the background and scope of this organisation's development activities as contained in their leaflet is given in Appendix 4).

The CHDRP worker from whose workload participants were recruited in this small organisation was female. All the participants interviewed were also female. (Participant profiles are displayed in Table 5.3 and discussed in the next chapter). A field note recorded during this visit was that gender issues were seen as important by workers and users alike and adult female participants were more likely to be recruited when female workers were employed.

A further group of participants recruited had been seen by a second type of community rehabilitation worker, community rehabilitation technicians (CRT). These workers were trained in an institute setting, the Centre for the Rehabilitation of the Paralysed (CRP). According one of the more senior CRT workers around twenty of these workers had been trained in Bangladesh at the time of the research. To arrange user recruitment, I obtained permission to present my request to CRT staff during one of their monthly staff meetings from the head of the Social Welfare department. Here I explained the aims and goals of the research, invited questions and asked for

volunteers to participate from the all-male group of CRTs attending. Three community centre leaders volunteered. I again specified that the only requirement for users was that they had been seen sometime within the previous year by a CRT worker. I also requested that we conduct the interviews with users in their own homes wherever possible, explaining how this would add to the richness of the data. Dates for the interviews were confirmed by mobile phone. On each of three visits subsequently made to rural clinics, we interviewed male CRT workers prior to going to the homes of users. On two out of these visits, it appeared that very little, if any, user recruitment had occurred prior to our visit. Nevertheless, five interviews with male service users previously seen by CRTs, did take place successfully.

4.3.7 Users Seen by Diploma and BSc Level Physiotherapists

Three user participants were recruited who had been seen by government-trained diploma level physiotherapists. All three participants were male and were recruited by a male physiotherapist newly appointed to a large government hospital in Mohakhali, a district in the capital city. The fourth participant was a mother whose son had been treated by a male newly qualified diploma level physiotherapist in CRP during his paediatric placement.

The final group of user participants had been seen by physiotherapists nearing or just after qualification at BSc level. Recruitment of these participants was again delegated to physiotherapy staff working in the outpatient department in CRP, who volunteered to do this. They recruited four males and one female user whose treating therapist was a female.

4.4 Section Four

4.4.1 Sampling Strategy for Provider Groups

The second target population were physiotherapists and related healthcare workers in Bangladesh. Purposive sampling was again used to include students and workers from each type of training and education courses in Bangladesh. These could be divided into three sets of two: two groups identified themselves as physiotherapy professionals. They were following courses leading to either degree or diploma qualifications in physiotherapy. Two groups were CBR workers whose status was closer to mid level workers and the final two groups were workers trained to address the needs related to

one specific impairment and were named accordingly. The numbers of each group available in 2004 was established through contact with the relevant authority. Approximate numbers of service providers available were shown in table 4.3.

4.4.2 Sampling Strategy for Professional Students

Initiatives in the field of physiotherapy in Bangladesh were a relatively new phenomenon. As I had been working in this field for over nine years, and this was a very new field in Bangladesh, I accrued this background information prior to the research by being immersed in this field but needed to confirm this through direct contacts with institutes providing training and education at the time. Training of professional physiotherapists was a relatively recent feature of life in Bangladesh. Institutes with established programmes of education for diploma or degree level courses were invited to participate. Where I did not know the directors personally I conveyed requests through personal contacts. The responses to invitations are shown in table 4.4

Table 4.4 : Institutes contacted and responses to invitation to participate

Institute	Type	Response to contact
National Institute of Traumatology and Orthopaedic Rehabilitation (NITOR)	Government	Participated BSc (Ord) Physiotherapy
Centre for Medical Education, (CME) Mohakhali, Dhaka	Government	Participated Diploma in Physiotherapy
Gono Bishwabidyaya	Private	Participated BSc (Hons) in Physiotherapy
Centre for Rehabilitation of the paralysed (CRP)	Non-governmental	Participated BSc (Hons) in Physiotherapy Diploma in Physiotherapy
Magura Clinic, Khulna	Provincial, non – governmental	Diploma in Physiotherapy - had been discontinued.
Peoples University of Bangladesh (PUB)	Private	No answer received in response to request made through physiotherapy teacher contact. BSc (Ord) in Physiotherapy

4.4.3 Rationale for Inclusion of Different Institutes

At the time of data collection there were seven institutes known to be offering physiotherapy education and training. Both diploma and BSc courses in physiotherapy were being offered. Six institutes were in the capital city and one a provincial institute. Two of these were government institutes, three were private universities and two were non-governmental organisations. Both government institutes were included in the sample as they offered different qualifications; one institution offering an ordinary

degree in physiotherapy and the second a diploma in physiotherapy. Information from the relevant government office in Dhaka around other diploma courses running in the country indicated that permission had been granted for three other courses to take place (in Dhaka, Bogra and Rajshahi) but no evidence could be found to indicate that these were running. The entrance requirement for diploma level courses was lower than for ordinary degree courses and students were drawn from different parts of Bangladesh. The government diploma course was also taught by medical doctors and was entirely in Bangla. Accordingly interviews with the students on the diploma course running in the Centre for Medical Education in Dhaka, (Institute of Health Technology), were also conducted in Bangla.

One of the two private universities educating to honours degree level agreed to participate, the second private university contacted did not respond to the invitation. The fourth institute to participate was CRP, a non-governmental organisation, affiliated to Dhaka University. This offered a four-year honours degree and a three-year diploma in physiotherapy. Successful diploma students in this institute only were allowed to upgrade to an honours degree. (This unique arrangement was widely viewed as a legitimate way to increase admission numbers to the degree course). The entry level qualification for admission to both diploma and degree courses in CRP was therefore comparable and diploma students were educated in the same classes as degree students. However, in addition to their BSc examinations, diploma students were required to complete examinations set by the government diploma examination body, the State Medical Faculty.

A fifth institute, the only provincial training institute in the country, was contacted but did not respond. A diploma course in physiotherapy was known to be running here in 2002. Although a treatment clinic was still functioning, it was confirmed that this course was no longer available. As two diploma courses were already included in the sample this institute was not considered further.

In total, five professional course groups participated from four different institutes (one institute, CRP offered both degree and diploma). Students from both the first and final years in each of the four institutes were invited to participate in separate focus groups in order to examine professional socialisation experiences.

4.4.4 Use of Intense Networking to Gain Access to Participants

Personal contacts established through previous work in Bangladesh, and subsequent employment in physiotherapy education, were utilised to gain access to participants from relevant organisations. I relied on these contacts to request a meeting for me with their director, if it was inappropriate for me to do this directly. In these meetings the research goals and requirements were then explained and permission sought to involve the project in the research. This step involved a lot of preliminary visiting. Flexibility was needed as plans often changed when strikes disrupted travel plans for some of these visits.

4.4.5 Pilot Provider Interviews

A pilot focus group and a pilot individual student interview were conducted with third year student volunteers in CRP. This was not the final year group as the BSc course here required four years study. The intensity of interest displayed by the students in these interviews was quite startling and was a good indicator of the level of participation to expect. The pilot interviews provided an opportunity for practical arrangements to be reviewed. The recording procedures and the transcript production and review procedures were also agreed on. The pilot transcripts were also discussed with the research assistant. They indicated a number of further areas of interest which were subsequently incorporated into the interviews which followed.

4.4.6 Recruiting Students from Professional Courses

In preliminary networking meetings arranged with course directors an emphasis was placed on the voluntary nature of participation in focus groups and interviews. It was stressed that there was no personal advantage to be gained other than the experience of taking part in a research activity. Both male and female participants were welcome and light refreshments would be available at the end of the discussion. Participants were to be recruited according to year group. This was the only requirement that needed to be strictly adhered to. In my own place of work, recruitment for focus groups and interviews was via a notice placed on the students' notice board. Students in first and final year groups were invited to sign up for groups and interviews scheduled in free sessions, according to the regular weekly timetable. No other notification was given in order that recruitment was entirely voluntary. This pattern was shared with the organisers in all participating institutes for diploma and degree

courses; however it appeared that recruitment strategy used in all other institutes was by word of mouth. This reflected the preferred mode of communication. Two of the recruiters were female, one was male and all were known by the researcher and taught the student groups in question.

At the start of the focus group meetings and individual interviews, the voluntary nature of participation was again stressed. It was then stated that the recording could be stopped at any point if required and that the students were under no obligation to answer questions with which they were uncomfortable. In all focus group interviews except one government diploma group, both genders were present. There appeared to be a reason for the absence of females in this particular group. There had been a series of strikes in their training institute resulting in the cancellation of several interview dates. Finally one arrangement went ahead but this was scheduled on a public holiday. When I arrived, I found that the location of the meeting had been moved to the male dormitory, hence, it was unsurprising that no female students attended. I had not anticipated this change of location. As this meeting had taken several weeks to arrange, I decided to proceed noting the exclusively male student presence. The female absence drew no comments from the participants.

Students were generally very enthusiastic to have their views heard and conversations were curtailed only by time constraints in almost all the focus groups. However, an exception to this which occurred with the first year government (BSc NITOR) students. Students here appeared to be much less opinionated and seemed to be fairly reserved and slightly anxious in comparison to all the other groups. I later dubbed them 'the quiet group' and I suspected that they were not actually physiotherapy students despite the fact that they all identified themselves as such. At a much later date, and after further enquiries about these group members, I discovered that NITOR had two student intakes per year and most of this group were in the 'second batch' of students admitted to the physiotherapy course. Due to almost continual strikes in this institute, most of the group members had little experience as physiotherapy students. As there had been only minimal contact with other year groups in this institute, they had been unable to engage in the customary networking with other students, and therefore had not had enough time to formulate opinions around most of the topics we introduced.

The details of focus groups and individual semi-structured interviews achieved with students on professional courses is shown in table 4.5.

Table 4.5 : Focus groups and individual interviews achieved

Institute	Focus groups	Interviews	Qualification
National Institute of Traumatology and Orthopaedic Rehabilitation (NITOR)	2 (1 final year 1 first year)	2 (1 final year 1 first year)	BSc Physiotherapy
Centre for Medical Education (Institute of Health technology) Mohakhali, Dhaka	1 (first year)	1 (first year)	Diploma Physiotherapy
Gono Bishwabidyalaya University	2 (1 final year 1 first year)	2 (1 final year 1 first year)	BSc (Hons) Physiotherapy
Centre for Rehabilitation of the Paralysed, CRP	2 (1 final year 1 first year) Pilot focus group (3 rd year BSc)	2 (1 final year 1 first year) Pilot interview (3 rd year BSc)	BSc (Hons) PT /Diploma in Physiotherapy
DBLM Nilphamari Leprosy training institute	0	5	Leprosy PT technicians
Institute Child Health – Dhaka School- Dhaka	0	5	Developmental therapists
Rural clinics	0	5	Community Rehabilitation technicians
CDD CHDRP Training institute	0	5	Community Handicap Disability Resource Persons

4.4.7 Recruitment of Providers from Related Healthcare Worker Groups

Related healthcare worker groups consisted of four different groups and the goal was to achieve five interviews with each type of worker. In all participating organisations for the healthcare workers, interview procedures proceeded according to arrangements made by the organisation. The gender ratios in resulting interviews often reflected the student and staff make-up in the organisations e.g. all developmental therapists in Bangladesh were female so participating developmental therapists interviewed from this group were all female. Overall the ratio of participants reflected a male bias which was noted. The recruitment of healthcare workers was arranged by link persons in the organisations as shown in table 4.6.

Table 4.6 : Recruitment of related healthcare workers

Type of Worker	Link person responsible for recruitment	Number of interviews arranged
Leprosy Physiotherapy Technicians	Manager of Leprosy Project	5 (4 male, 1 female)
Developmental therapists	Liaised with retired director of school	5 (All female)
CHDRP workers	Staff member of training Institute (CDD)	5 (3 male, 2 female)
CRT workers	Social Welfare Officer manager in CRP and sub-centre managers	5 (3 male, 2 female)

The interviews arranged with the related healthcare workers were arranged through the link personnel noted in table 4.6 above.

4.5 Section Five

4.5.1 Data Analysis

Qualitative data analysis is a continuous, iterative process described by Miles and Huberman (1994, p.24) as 'moving up a step on the abstraction ladder'. Spencer, Ritchie and O'Connor in (2003) use the analogy of a ladder to depict the stages and processes of qualitative analysis illustrating the ascent from descriptive to conceptual accounts (Figure 4.1). The analysis of both user and provider groups followed the process displayed in the 'ladder illustration' below:

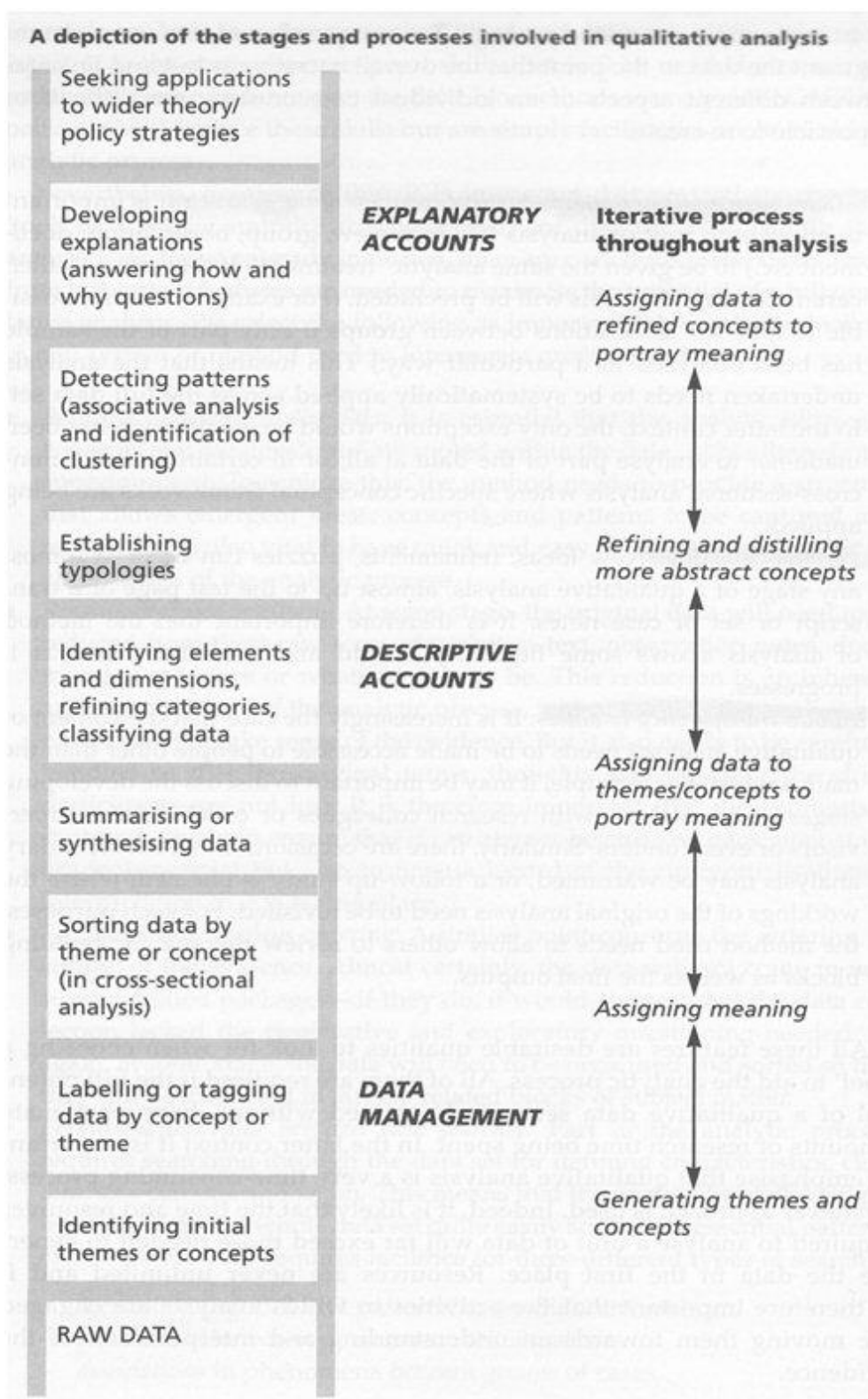


Figure 4.1 : A depiction of the stages and processes involved in qualitative analysis
 Taken from Spencer, Ritchie and O'Connor 2003, p.212

The data analysis followed a plan, which is shown in Fig. 4.2 below.

The user group analysis enabled the first research question to be answered. The subsequent provider group analyses enabled the second research question to be answered and a further systematic comparison of each provider group analysis with the user group analysis informed the third research question.

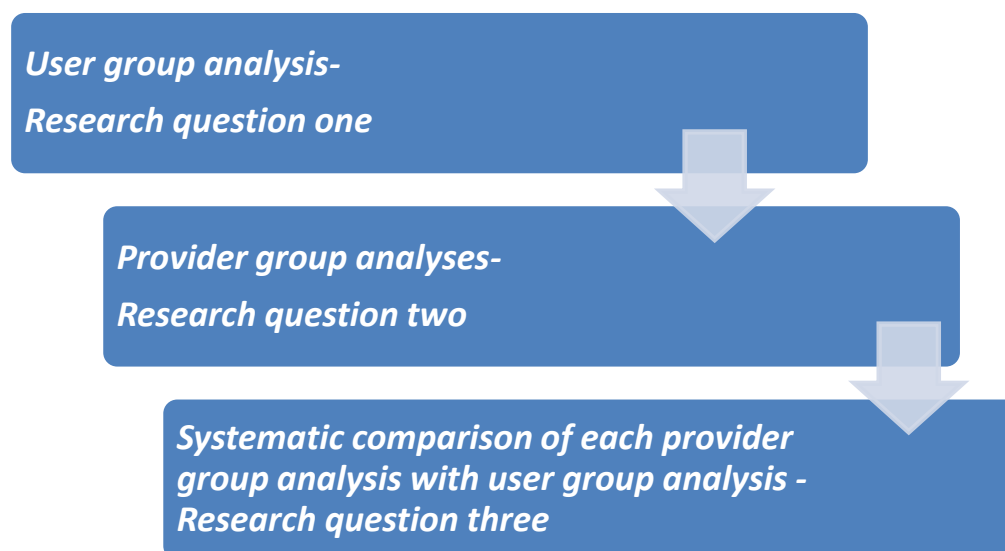


Figure 4.2 : Plan for data analysis

4.5.2 Translation Issues

The raw data recorded in interviews and focus groups was mainly in Bangla with some parts in English. These were transcribed and translated into English script by the research assistant. In translating Bangla into English it is relevant to note that Philips (1960, p.129) described the position of ‘conceptual equivalence’ across languages ‘as an insolvable problem’ since ‘almost any utterance in any language carries with it a set of assumptions, feelings and values that the speaker may or may not be aware of but that the field worker, as an outsider, usually is not’. It is suggested that the meaning of any non–English text cannot be solely confined to words on the page. The accuracy of the representation of non–English speakers in English will therefore always only be, at best, an attempt to represent what was communicated. Accuracy of the transcripts was therefore an area of particular attention.

Language usage in the transcripts was discussed at length. If a Bangla word or phrase used by the research assistant was one that I would have expressed differently in English the phrase was changed. An example of this was the use of the word ‘genie’ by the assistant, which I changed to ‘spirit’ explaining that this was the word best

matching. Another example was use of the word neglect. The phrase, 'he neglected my presence' in the transcript was changed to 'he ignored me' as a better English translation of the description by a student about a doctor's behaviour towards him.

Consideration was given to hiring a translator to check the accuracy of the translation using backwards and forwards translation but costs were prohibitive. This would also have introduced the need to consider the further impact of another translator on the data. According to Temple and Young (2004, p.171) 'the translator always makes her mark on the research whether this is acknowledged or not...' I was also moving back to the UK after the data collection and therefore chose instead to work with the research assistant on producing the best transcripts in-situ prioritising the ongoing process of discussion and debate around meanings. These discussions with a national who had experienced and been part of all the interviews himself became key to interpretation and analysis. On-going analysis was in English. The field notes and relevant course documents were examined alongside the transcripts referring to relevant parts appropriately, as the analysis progressed in an iterative fashion.

4.5.3 Activities in Data Analysis

Miles and Huberman (1994) describe the key features of qualitative data analysis as three concurrent flows of activity: data reduction, data display and conclusion drawing/verification. Data reduction began prior to the fieldwork as decisions are made to focus the research by refining the research questions, selecting the sampling criteria and determining the topics to include in a preliminary topic guides. Data from the pilot interviews, ideas from the literature and personal knowledge gained in Bangladesh were drawn upon to refine and modify these. Data reduction continued in stages; focusing, selecting, summarising and abstracting data both during and after fieldwork had been completed. Data display required an on-going presentation of data in a structured and organised manner in order to provide a transparent account of the decisions made and the processes involved in data analysis. Conclusion drawing and verification of conclusions represent the process of deciding what things mean and then testing these meanings in a cyclical process of induction and deduction. Induction, as themes and patterns were identified from the data, and deduction, as emergent ideas were tested with subsequent data collection.

Stage one: User Analysis

The Initial thematic ideas in the field notes and interviews of users were noted, giving them a label and noting the passage and noting the themes in a memo. Several themes were evident and these were listed. These related to other themes and could be grouped together and labelled under a group name, which was given a code. Some of the themes were purely descriptive; being cheated, searching for a cure etc. As the interviews progressed, the transcripts were compared repeatedly, looking for comparable themes and marking the text with the same code when these were identified. Codes gradually became more analytical e.g. loss of status, ascribing value to interventions. These could also be grouped into structured explanations at personal, cultural and structural levels utilising concepts found in the literature.

At this stage, the breath of experiences and compounding factors needed a clearer analysis. This necessitated returning to the literature, searching this in greater depth in order to widen my own understanding and achieve a better grasp of the theory. Armed with this, I returned to the data and repeated the process, looking for new categorisations and associations, re-visiting and interrogating the scripts in order to identify elements and dimensions with greater clarity. The user transcripts were again searched sub-group wise and as a larger group.

Stage two: Provider Group analyses

The user group analysis was followed by provider group analyses. The provider group analyses occurred group-wise, and also followed an iterative process. As one set of group interviews was completed, and data collection moved on to the next provider group, it was possible to use insights cumulatively and recognise recurrent themes and patterns of association beginning to appear in the data. For professional groups where focus groups and individual interviews from each year groups occurred, these were considered to be part of the same data set for that year group. It was also necessary to return to the literature and read in greater depth, grasping a greater appreciation of educational theory, which enabled clearer explanations to be made for what the data revealed. Following each group analysis, different provider groups could also be compared by searching for contrasting patterns and linking this with information from course documents and field notes, in order to synthesise explanatory accounts. It was

important to link ideas with theory, and this was helped by a wider reading of the literature. A further strategy was possible with the professional courses. Characteristics of first year groups were compared with those seen in students in final stages (or just after course completion) in order to identify the role professional socialisation was playing in development of professional characteristics. This was not possible with the alternative workers trained over much shorter periods of time. These groups were working in their fields and were asked to reflect on the experiences they had had which influenced their understanding of user needs and the role they had.

Stage three: Group Comparisons with User Analysis

The third stage of analysis involved comparing the analysis of each provider group with the composite user group analysis. Course documents, literature and field notes again helped to develop the final stage of analysis and answer the third research question.

4.5.4 Rigour in Qualitative Research.

Qualitative and quantitative researchers use different methods to achieve rigour in their research. Traditionally quantitative researchers have focused on establishing the validity and reliability of their instruments. Blaikie (2000, p.246) points out that on examination of these methods it is evident that they involve corroboration and replication. In qualitative research, as the researcher is usually the measuring instrument and no two instruments are the same, this makes corroboration and replication more difficult, if not impossible, to achieve as researchers produce their own unique accounts. Some qualitative researchers would claim that if a researcher has acted professionally, and has explained how they went about their research, their accounts can be trusted. Lewis and Ritchie (2003, p.276) suggest that member or respondent validation can contribute to full 'confirmation' of a finding from a qualitative study. This involves taking research evidence back to the research participants (or to a group with the same experience or characteristics) to see if the meaning or interpretation assigned can be confirmed by those who contributed to it in the first place.

Time and financial constraints and the difficulty of accessing particular situations in Bangladesh in which the data were obtained made it extremely difficult to return to the participants' homes in order for them to check through the accounts and verify

their accuracy. Illiteracy would also have been a problem to overcome with several of the participants and therefore this was not attempted. The following measures were taken in order to verify the degree of accuracy in these final constructions. Four newly qualified physiotherapists were asked whether they could support students' perspectives in the final accounts. All four had moved to the UK and it was possible to meet them. A further four people were also asked to validate descriptions of users and students. These included one Bangladeshi physiotherapy teacher and one Bangladeshi physiotherapy staff member with whom I had contact. Two female expatriates with lengthy experience in the paediatric healthcare field in Bangladesh also verified the user accounts. All the recordings from which the transcripts were produced were kept in the possession of the main researcher.

4.5.5 Generalisability to Other Contexts

Qualitative research aims to study people in their own environment, the 'natural' setting (Lincoln and Guba 1985) and to also provide 'thick descriptions' of the settings (Geertz 1973). This required writing extensive field notes of observations and compiling personal accounts and detailed narratives from transcribed data in order to generate grounded theory. Additionally information about courses contained in curricula or from key informants was studied. Capturing rich data in natural environments meant it was important to enter the natural environments. This entailed conducting interviews with users in their homes or in clinics and, for students and workers, in classrooms and places of work.

The 'thick descriptions' enable a consideration of transferability of findings to other settings or populations based on similarities and differences between settings. Findings are thus context specific but because of similarities elsewhere may have relevance to other settings in their application. Lincoln and Guba (1985) refer to this as the degree of congruence between the 'sending context' within which the research is conducted and the 'receiving context' to which it is to be applied.

4.5.6 Ethical Considerations

No official body existed in Bangladesh from which ethical approval was required. I therefore applied general principles of ethical concern to the study.

The voluntary nature of participation and the need for informed consent was stressed when liaising with all contacts and participant recruiters. However, as there was no direct contact with participants prior to the interviews, these issues were revisited before commencing all interviews. Information was given around the purpose of the interview, how information would be used and how confidentiality of all participants would be addressed. The use of pseudonyms was explained along with an assurance that no details would be reported which could lead to the identification of an individual.

It was unclear to me how much the idea of freedom of choice to participate was understood by participants. The concern was that in such a hierarchical social setting users or students may be reluctant to refuse to participate, if the invitation was conveyed by an authority figure. Both the research assistant and I were therefore careful to actively look for, and respond to, any non-verbal indication of a reluctance to participate at any time during the visit. I assumed overall responsibility to curtail an interview if there was any sign that it was not appropriate to continue.

The well-being of the participants both during, and after interview, was considered especially in view of the numbers of onlookers sometimes present. One interview was curtailed because I judged that it was unhelpful for the participant for this to continue.

Throughout the research process, I was employed as a practitioner/educator in one of the participating organisations and supported by a grant from a UK charity. Both this employment and my previous employment in the south of the country had linked me in various ways with participating organisations and I was able to use these networks in order to set up the study. This wider engagement over several years meant that I did not feel bound in a way to display a particular allegiance to any one organisation.

4.6 Section Six

4.6.1 A Reflexive Account of the Researcher as a Research Instrument

As I was an experienced physiotherapist, working in a NGO educating national physiotherapists and treating patients myself it was unlikely that I could claim detachment in data collection. I had already formed some opinions about the lives of disabled people and the aspirations of trainees before the research began, which influenced the way I thought and reacted to all I saw and heard during the data

collection. Therefore, being actively reflexive was very important throughout the research process.

I was very conscious of the fact that disability theorists have drawn attention to the power imbalances between those who research and those who are researched (Oliver 1997) and that debates existed around non-disabled researchers attempting to research the lives of disabled people (Stone and Priestley 1996). I therefore questioned whether I, as a non-disabled foreigner from a developed country, could gain access to perspectives of Bangladeshi disabled people and to Bangladeshi students and staff. These were certainly important considerations. It was impossible to eradicate the power, culture or physical differentials however and I chose instead to remain aware of how these may be affecting the data generated. This meant remaining consciously interactive throughout the data processes, answering questions and providing specific information myself when asked, taking advice from nationals in developing the topic guides and in practical arrangements, responding to their suggestions and checking interpretations regularly. In the focus groups, the position I adopted and encouraged the research assistant to adopt, was to avoid presenting ourselves as experts and seek to be attentive and sensitive to participants' experiences (Barbour and Kitzinger 1999).

Both my own and the research assistant's observations were discussed and compared during and after every visit. I was repeatedly struck by elements of the material environment in which interviews were held e.g. the lack of basic physiotherapy equipment, or the very low standards of cleanliness. In village homes I frequently commented upon the material starkness and un-adapted home environments whereas the assistant was, clearly, a lot more interested in finding out and commenting on the personnel encountered and their wider activities and connections. This reflected the strong emphasis on relationships, a feature of Bangladeshi culture with which I had become familiar. The research assistant could also not claim to be completely objective in the data collection, and his position as a national also impacted the data; he was a recently qualified physiotherapist, similar in age and background to many of the participants in the professional trainee groups and he had the same issues, concerns and aspirations as many of the participants. He had also previously researched the views of carers of disabled people as part of his studies and this knowledge also meant that it was unrealistic for him to adopt a detached observer

position. The position adopted was therefore to recognise the ways in which we both influenced data generation as research instruments with different value systems. (The research assistant gave a reflexive account of the interviews at a later date. This is shown in Appendix 5).

As the interviews progressed I became quite conscious of the fact that my reaction to the situation of female disabled participants was quite different to that of the assistant. Reflecting on this, I realised there was cultural and gender distinctiveness operating between us during the data collection process, and this needed to be acknowledged. This alerted me to the importance of recognising gender stratifications in the society and how these affect all aspects of the research. One particular instance recorded in the field notes was very relevant to this aspect of the analysis and is therefore recounted below.

This incident occurred whilst visiting homes in a village area in order to interview users previously seen by one of the CRT workers. We were taken to a home of a disabled young woman in a rural area by a CRT. We established fairly quickly, however, that she had not actually been treated by the CRT worker despite his detailed knowledge of her predicament. Although we did not proceed with the interview because she did not fit the inclusion criteria, several details recorded in the field notes were pertinent to the research inquiry.

On entering the compound of four houses, we saw the young woman sitting outside her parents' home on a mud wall. She was knitting. She had cerebral palsy mainly affecting her lower limbs, and her speech was slurred. She was dressed in an ill-fitting and very dirty sari blouse and petticoat and the thick calluses on her limbs and severe lower limb contractures, suggested she moved around the compound by crawling on all fours. She was able to converse, albeit slowly and with slurred speech, and responded appropriately to my questions after we had introduced ourselves. I asked her how old she was, knowing that this was a difficult question for many people in Bangladesh. She responded directly by telling me she was 24 years old and laughed loudly when I replied, jokingly 'Same age as me!'

She had a number of siblings, all of whom were educated. Her mother and one of her siblings were present. Her sister was clean and very smart in appearance wearing a

fashionable shalwar³ chemise. I was informed that her father was a government worker. After chatting with the family members for a while, we decided to leave as the crowd was building up and filling the compound area. I felt however, it was appropriate to offer the opportunity of wheelchair training for the disabled young women and asked if I could speak privately to her mother at the side of the house. Her mother listened but seemed totally disinterested in the offer. The reason she gave was that she did not feel it was worth bothering to do anything as this was a female and there was no point, particularly as she would never get married.

As we walked away, the CRT worker related that the family had buried her to the waist during a lunar eclipse in an attempt to obtain a cure – a practice I knew happened in India. What was significant to me was that the male CRT worker said he also thought she was not worth treating and laughed as he related the lunar incident which he described as making a ‘standing frame’. This incident served as an illustration to me that the attitudes of some of the workers towards rehabilitating disabled females were similar to those of the community members and the incident led me to reflect on the need to consider carefully gender issues in workers. I also noted the incident did not appear to perturb the research assistant to any degree and this highlighted to me how much value systems were bound up in the inquiry.

In this research, the impact of my identity as a foreigner needed to be noted. Many of the users had no previous direct contact with an expatriate prior to the data collection. As a female fair-haired foreigner, I was a huge source of interest particularly in the village locations and quickly became the subject focus of intense scrutiny. I was obliged to answer a barrage of personal questions about myself, my country and the purpose of the visit on every trip to a rural location. On one occasion, the crowd which had gathered applauded several times in response to my answers to questions about myself. Before leaving they thanked me profusely for coming to their village and for considering their experiences to be important. This second reason both surprised and humbled me as I reflected on the lack of attention paid to the views of poorer patients in the hospitals.

³ Typical Asian female dress

My presence seemed to have the effect of imbuing these occasions with a sense of great importance for all participants, especially those in the more rural locations. Participants appeared to answer the questions carefully and thoughtfully and members of the crowd or family members often joined in enthusiastically augmenting answers they were giving. This added to the richness of the data even though it made the task, at times, more difficult with repeated requests needing to be made to allow the person asked to respond to the question.

Exchange of personal information is seen as part of normal life in Bangladeshi society and is not considered intrusive by nationals. I therefore regarded the exchanges of personal information about myself as a necessary preliminary to establishing trust and rapport with participants in their own communities and on their own terms. I also regarded these exchanges as opportunities to put participants at their ease and develop rapport in the first stage of the interviews. It appeared that being open and responsive did help to reduce suspicion around my motives. Momin (2003) had reported considerable suspicion of his motives in research with disabled people in the community in Bangladesh and I therefore anticipated that this would happen and considered carefully how I could reduce this. One way was to allow interview organisers as much control as I felt was reasonable and would still provide me with access to user experiences. Although this introduced the possibility of bias, where only users with positive viewpoints would be recruited, it was also a practical arrangement that increased the possibility of gaining access.

Despite this plan, there was still evidence of considerable suspicion throughout the data collection. This was especially marked where I was less known to individuals involved and much less with students I had taught. The instances of suspicion included covert and overt activities e.g. on one occasion the research assistant established from relatives during the course of the afternoon, that our guide was the husband of the staff who had seen all the users we were interviewing. Her husband also worked for the organisation but gave no indication of this fact himself. On a further occasion, a car trailed our small group of four people until we took a path off the road into a village where a participant lived. After returning to the road, the car reappeared and suddenly a male occupant jumped out and quizzed me in great detail about my identity and the purpose of our visit. He then identified himself as the local chairman of the area.

A further impact I was aware of in several interviews with students and healthcare workers was that they were reacting to me as a foreign physiotherapist rather than as a researcher. This meant that the students sometimes appeared to use the focus group as an opportunity to lobby for my support to represent their needs for post creation to the government, or to insist that I should try to procure equipment for them from UK. This was not unfamiliar territory to me as the use of personal contacts to achieve action was the customary *modus operandi*. My identity as a physiotherapist may also have influenced participants to assume that, in discussing user needs, I wanted to hear about physiotherapy. As this element could not be removed, it was important to acknowledge its impact on the data collection.

4.6.2. Reflections Around Working in a Second Language

Although all the institutes educating to degree standard in physiotherapy expected students to have a grasp of English, the standard was very variable. It was decided therefore, that the interviews would be in whatever language participants chose. Data recorded with students was, in reality, a mix of English and Bangla. Interviews were transcribed fully into English by the assistant who had excellent language and computer skills.

Because Bangla was a second language for me, it was decided that, after the arrival and introductions, the research assistant would lead the interviews. However, if questions were directed towards me in the interview I would respond. Also, if I felt that further probing or clarification seemed appropriate, I would intervene. To do this I waited for a natural pause in the conversation or until the end, if the discussion was flowing.

Before and between interviews I coached the research assistant regarding the need to maintain a conversational style and in the focus groups to maximise participation. This was done, for example, by asking females only and then males only for their comments or by asking if everyone agreed with the view expressed to invite comment from quieter members. I noticed that the research assistant sometimes reverted to a rather sharp question and answer style, particularly with participants of lower social status. I recognised this as a form of cultural authoritarianism. Maloney (1991) notes that in Bangladesh, persons of superior social ranking commonly speak sharply to

subordinates who, in turn, are not expected to offer an opinion on a subject unless asked. It was noticeable that, when this occurred, the participants seemed to accept readily this pattern of communication and were not unduly perturbed by it. For me this was a very interesting observation. I linked it to the contrasting styles of communication between foreigners and nationals I had previously observed. Some foreigners, like myself, clearly tried to maintain a style that was culturally their norm interacting with nationals on an equal footing, but other foreigners adopted a more 'command and control' style used by nationals speaking to those of lower rank.

Many of the interviews with the BSc students and some of the other health worker groups were spoken using a mixture of English and Bangla words. Students often began in English but reverted to Bangla or to a mixture of Bangla with English words or phrases inserted, when they became animated, or disagreed with other group members. In one focus group with diploma students in a government institute, interviews were almost entirely in Bangla and, in a very small number of individual interviews with physiotherapists, almost entirely in English. An assessment and evaluation of the researcher and the assistant, who were both, at different times, working in a second language in gathering the data, was therefore important.

Working in a second language as a researcher seeking to capture the 'insider view' was a challenge. This was greatest when users had no English at all and lived in the more remote rural areas. Although I had worked for four years in rural leprosy hospital and a general hospital, and for a further five years in the capital with patients and students, I found that following these conversations required intense concentration. This was perhaps because the topics discussed and vocabulary used was less familiar to me. I noted in these interviews that the assistant's phrases became increasingly colloquial, matching the participants' language somewhat and this increased the difficulty I experienced in following these conversations. Discussion around the content of these interviews directly afterwards with the research assistant was therefore especially valuable and necessary, as I was eager to compare my interpretation of the exchange with the assistant's understanding. Scrutiny of the transcripts together led to more discussion of situated meaning for the speakers, whose social positioning differed markedly at times from not only from my own but also from that of the research assistant's.

Temple and Young (2004) state that academics have long recognised the importance of language in constructing as well as describing our social world. They point out however, that the relationships between languages and researchers, translators and the people they seek to represent, are as crucial as issues of which word is best to use in a sentence. The research assistant's educated status and language ability and my own level of fluency influenced both content of interviews and language choice used in the transcripts.

It was important to acknowledge all the impacts above, on both the data collection and the analysis. Despite the barrier that working in a second language undoubtedly introduced, the fact that I could communicate in Bangla appeared to increase participants' willingness to trust the sincerity of the research intentions and helped to create a climate of trust. This added to the depth and richness of the data it was possible to obtain.

4.6.3 Chapter Four Conclusion

The chapter has described the way in which the methodological decisions were made and also attempted to provide a comprehensive account of how the research strategy was chosen and implemented. The research process was adapted to the context in which it occurred and the position of the researcher, as an instrument, has been discussed. The following chapters will present the findings of the study analysis in a sequential manner.

Chapter Five

5. VIEW FROM THE INSIDE–THE LIVED EXPERIENCE OF DISABILITY

5.0 Introduction

The purpose of this chapter is to outline the study findings of the ways in which participants, who have accessed services provided by physiotherapists and related healthcare workers, perceive their experience of disability and to draw out implications from these findings. The chapter presents conceptualisations around the cause of impairment, perspectives around interventions, and expectations of the society. It stands therefore as a key informative chapter in the study, highlighting the voices of disabled people and parents of disabled children who have received interventions from different types of workers. Of particular importance are the messages in the chapter, which emerge and can inform the education of these practitioners. These are summarised after each section.

Against the backdrop of this chapter, subsequent chapters will examine the different perspectives and educational experiences of physiotherapy students and related healthcare workers being prepared for and working in his field.

The chapter has four sections. Section one describes the data set used in the user group analysis. Section two focuses on the rationalisation around the cause of impairment by participants, their families and wider community. This section also looks at changing beliefs around impairment and considers the effect of individualistic approaches in a collectivist society. The impact of community approaches to health education is also considered in this section. Section three reports on the experiences of gaining access to therapeutic services, and subsequent evaluations of these and other interventions. Section four then looks at the wider material impacts of impairment and the knowledge of the rights of disabled people held by the participant. This section also explores the participant's perspectives around society's obligations to them. Each section draws out issues of relevance to education of healthcare workers from these findings. A chapter conclusion is then drawn.

5.1 Section One

5.1.1 Construction of the Data Set

A goal of 30 user interviews was established. This was drawn as widely as was realistically possible in order to capture a spectrum of views of users seen by all types of workers trained for this field, aiming to include equal numbers of users seen by each group. Participant details including gender, age, location of interview, source of family income, type of impairment of user and relationship of participant to user. These are presented group-wise in Tables 5.1 to 5.6. They are identified in the script numerically according to the type of healthcare worker seen. Points that were significant for each group are also noted group-wise and other information of relevance to the data collection is described.

5.1.2 Participants Seen by Leprosy Physiotherapy Technicians

All male and female users in this group had been treated by a leprosy physiotherapy technician (Lep U) within the previous year. Participant details were collected from patient files or gathered from the participants themselves and are shown in Table 5.1 (See Appendix 7 for details of the leprosy project from which participants were drawn.)

Table 5.1 Profile of participants seen by Leprosy Physiotherapy Technicians (LepU)

Participant Identification	Location of interview	Gender of disabled person	Age	Income source	Impairment	Interviewee
FLepU1	Rural leprosy clinic	Female	20	Unemployed Husband works	Minor sensory and motor impairments of feet and hands	User
MLepU2	Rural leprosy clinic	Male	75	Retired, wife earns	Multiple health problems affecting communication. Unsteady	Wife
MLepU3	Rural leprosy clinic	Male	Early 30's	Unemployed, previously daily labourer	Limbs -minor weakness and sensory loss	User
MLepU4	Rural leprosy clinic	Male	Late 20's	Keeps cows	Sensory disturbance and weakness in both hands	User
MLepU5	Rural leprosy clinic	Male	70 - 80	Retired – no income	Severe visual loss, loss of all digits.	User
FLepU5 (Female Carer of Lep U5)	Home of U5 – outside	Female	40	Housewife, no income	Nil	Carer of U5 (Daughter)
Key: M: male, F: female, LepU: Seen by leprosy technician, U: User, FC: Female carer						

The age-span in this group was from twenty to between seventy and eighty. The age of the participants was estimated for those participants unable to say what their exact age was. The records of each participant were scrutinised prior to the interview. These were medically orientated. A small section only recorded the social history. Four males and three females were interviewed. Two of the females were carers. One elderly male interviewed had a number of medical problems and his wife answered most of the interview questions. Only one male in the group had a source of income. The six interviews recorded included a visit to the home of an elderly participant.

5.1.3 Data Collection from Participants Seen by Developmental Therapists

The second group of users to be interviewed were all parents of disabled children who had been seen by developmental therapists. Only three of the five interviews hoped for were actually conducted. These all took place in the capital city, Dhaka. The first location for these was Kalyani Special School for Disabled Children. Two further interviews took place in a Treatment and Assessment Unit in the National Children's Hospital, Shishu Bikash. Both organisations are part of Bangladesh Protibondhi Foundation (See Appendix 8 for details of this organisation). Profiles of the three participants are shown in the table below. The parent of the female child in this group was also a staff member in the school.

Table 5.2 Profiles of Participants seen by Developmental Therapists (DT)

Participant Identification	Location	Gender of the child	Age of the child	Income Source of family	Impairment	Interviewee
FPDTU1	School for disabled children	Female	8	Father Income tax Officer Mother School staff	Cerebral Palsy	Mother
FPDTU2	Government Hospital Child Assessment Unit	Male	5	Father Carpenter Mother Unemployed	Autistic Spectrum	Mother
MPDTU3	Government Hospital Child Assessment Unit	Male	4	Father Agricultural Worker Mother Unemployed	Cerebral Palsy	Father

Key: P: Parent, M: Male, F: Female, DT: Seen by Developmental Therapist, U1: User 1, etc.

I was allowed to proceed with only one interview in the first location as two interviews had already been cancelled (This was discussed previously in section 4.3.5). The second location where users seen by developmental therapists were interviewed was a Child

Assessment and Treatment Unit in a large Government Children’s Hospital in the capital city. The founder and director, a paediatric consultant who was the daughter of the retired founder of Kalyani Special School, arranged these interviews. Both interviews planned here with parents proceeded. The director here was very supportive of the research and supplied information about plans for formal developmental therapy training in Bangladesh which were still awaiting government approval.

5.1.4. Participants Seen by CHDRP workers

The next group of five users interviewed had been seen by CBR workers known as Community Handicap and Disability Resource Persons (CHDRP). The small development community project chosen, Association of Development for Economic and Social Help (ADESH) runs a micro finance programme and is concerned with social rights (Appendix 4). As part of its development activities three CHDRP workers were employed to address the needs of disabled people. One of these was female. These workers had been trained to give basic physiotherapy treatment and arrange varied supports according to the needs of the family. Four female participants were interviewed in their homes. Their profiles are shown in the Table 5.3 below.

Table 5.3 : Profiles of Participants seen by Community Handicap and Disability Resource Persons (CHDRP)

Participant Identification	Location of interview	Gender of disabled person	Age	Income source of family	Impairment	Interviewee
F CHDRP U 1	Inside home-near build up area	Male	60-65	Retired Government Officer.	Hemiplegia Post Stroke – speech impairment	Wife
FP CHDRP U2	Inside home near built up area	Female	9	Father’s Business	Severe brain damage.	Mother
F GP CHDRP U3	Village home	Male	12	Not known	Cerebral palsy independently mobile	Grandmother, (main carer)
F CHDRP U4	Village home	Female	70’s	Retired	Multiple health problems	User (female)
Key: M: Male, F : Female, U1: User 1 etc., GP : Grand Parent, CHDRP: Seen by Community Handicap Development Resource Person						

One participant was the wife of an elderly man who had had a stroke and had marked residual speech difficulties. The second was a mother whose daughter had severe brain damage resulting in little movement and no speech. A third was the main carer of her disabled grandson. The fourth participant was an elderly lady with multiple health problems. Worker allocation was made according to gendered social norms for this group of workers. All families had been seen by the same female CHDRP worker. Participants seen by female CHDRP workers were either females with impairment or female carers of disabled adults or children.

These interviews took place on the weekly public holiday during the rainy season. A senior member of staff from the organisation accompanied the research assistant and myself to participants' homes in a nearby semi-urban area. We waded in warm knee-deep water in narrow gullies to get there. One house was accessible only by crossing a narrow bridge festooned over a heavily chemically polluted river. The user in this instance could only stand with support and was unable to cross the bridge. This meant that he was effectively marooned in his own home.

5.1.5 Data Collection from Participants Seen by CRT Workers

The next group of participants were also seen by community workers known as Community Rehabilitation Technicians (CRT). Although most CRT workers saw patients in small clinics, some home visits were made and I specifically requested that we interview users in their homes wherever possible. This occurred for three out of five participants and involved lengthy journeys in two cases. Two of these interviews took place outside these simple dwellings as we were not invited inside. Participants profiles are given in Table 5.4.

Table 5.4 : User Profiles – Participants seen by Community Rehabilitation Technicians

Participant Identification	Location of interview	Gender of disabled person	Age of disabled person	Income source of family	Impairment	Interviewee
MCRTU1	Village clinic	Male	Early 20's	Unemployed BA Student Father earns	Hemiplegia post heart surgery	User
MCRTU2	Inside village home	Male	45	Wife earns	Post stroke-severe mobility Problems unable to walk independently	User
MCRTU3	Open air in village compound	Male	60's	Potter - Son was doing father's job	Post stroke-moderate mobility problems	User
MCRTU4	Rural clinic	Male	17	Student Father earns	Accidental injury - arm impairment	User
MCRTU5	Outside tin shed home in town	Male	30's	Unemployed	Post stroke moderate mobility problems	User

Key: M: Male, F: female, CRT: Seen by Community Rehabilitation Technician, U1: User 1 etc.

All participants in this group were male and all had been seen by male CRTs. Islam prohibits physical touch between male and female adults unless they are closely related (Ahmed 1988). It was noticeable that adherence to this principle was being followed where possible. However, prior to one home visit, we did observe a male CRT assess and treat a young woman with low back pain in one rural clinic. She wore a burqua throughout the session and was accompanied by an older female. The CRT worker struggled to make sense of her symptoms. Two of the three rural clinics visited did have a female CRT and in one of these we observed a female CRT treating a male child. All three rural clinics were poorly equipped and lacked basic furniture and walking aids. No toys, mats or other equipment normally seen in a children's treatment environment were visible and the female worker used a large white plastic chair to assist the child to walk. Observations during these visits drew my attention, as an experienced physiotherapist, to both the poor levels of knowledge displayed by some of the CRT workers and to the urgent need for equipment.

5.1.6 Participants Seen by Diploma Level Physiotherapists

Two further groups of participants were chosen from users seen by professional physiotherapists educated to either diploma or degree levels. The first of these groups consisted of four user participants who had seen professional physiotherapists

educated to diploma level within the previous year. Their profiles are shown in Table 5.5 below.

Table 5.5 User Profiles - Participants seen by Diploma Level Physiotherapists

Participant Identification	Location of interview	Gender of disabled person	Age of disabled person	Income source	Impairment	Interviewee
MDipPTU1	City Government hospital outpatient department	Male	40's	Clerical Government worker	Recurrent neck pain	User
MDipPTU2	City Government hospital outpatient department	Male	40's	Hospital Admin worker	Recurrent spinal pain	User
MDipPTU3	City Government Hospital ward	Male	60's	Unemployed	Hemiplegia and spinal pain	User
FPDipPTU4	CP Child Unit Institution	Male	5	Unemployed housewife	Cerebral Palsy	Mother
Key: M: Male F: Female, Dip PT : Seen by diploma level physiotherapist, U: User 1 etc.						

Three male participants were interviewed in a large government hospital in Mohakhali in the capital city. The fourth was the mother of a male child who had completed a 14-day residential programme for mothers of children with cerebral palsy in the Centre for the Rehabilitation of the Paralysed (CRT).

5.1.7 Participants Seen by BSc Degree Level Students

The final group of users were seen by physiotherapists nearing or just after qualifying with a BSc in physiotherapy. They were interviewed in a variety of locations and these interviews were also arranged through physiotherapy contacts known to me. Three participants were interviewed in institute settings, one in an urban home and one in a remote rural village area. Their profiles are shown in Table 5:6 below.

Table 5.6 : User Profiles: Participants seen by Degree Level Physiotherapists (BSc)

Participant identification	Location of Interview	Gender of disabled person	Age of disabled person	Family Income source	Impairment	Interviewee
MBScU1	Remote Village home	Male	22	Small shop	Tetraplegia post spinal cord injury	User
MBScU2	Urban flat	Male	50's	Business	Mechanical spinal pain	User
FBScU3	Ward Specialist Institute	Female	24	Housewife, unemployed	Spinal Cord injury – paraplegia	User
MPBScU4	Private hospital department	Male	7	Father self employed	Cerebral palsy	Father
MPBScU5	Specialist CP Centre	Female	14	Father- art teacher	Cerebral palsy	Father

Key: M: Male, F: Female, P:Parent, BSc : Seen by graduate level physiotherapists, U1: User1 etc.

5.1.8 Gender Ratios in Participants

The data set represented 7 children and 19 adult service users. Their ages were spread over 7 decades so the reported experiences represent aspects of disability occurring at any point in a normal lifespan and from both genders. The gender balance of the 27 transcripts finally achieved was 16 male and 11 female participants. This raised awareness for me that the predominant voice in the data set was more male than female. The data also reflected the observation of more males than females were accessing services. Male staff outnumbered females in all work locations visited, except in children's services where employed therapists were all female. However, both male and female students on professional courses were given experience of treating children during their training and one mother interviewed was seen by a male physiotherapist completing his internship.

Only 3 of the 19 adult users who had accessed services in relation to their own impairment were female. Also, more parents of male children than of female children were interviewed.

Qualitative research does not set out to investigate the incidence of these phenomena in the wider population but the gender observations seen regularly suggested more males than females were accessing services. This recurrent observation supported reports that Bangladeshi society is highly gender stratified and boys are preferred (Akman 2002). In this sample the children (under sixteen) represented, included 5

boys and 2 girls. Parents of both girls represented were teachers at the respective institute providing the services and lived in urban areas. Both families were well educated and relatively secure socio-economically and both had relatively easy access to physiotherapy. Although investigation of gender discrimination in service uptake was not the main purpose of this research, observations consistently pointed to a bias towards males, and suggested that only the more educated and wealthier families were seeking out services for girls. Although this topic requires careful further investigation before any firm conclusions can be drawn, initial observations suggested consistently that the patriarchal nature of the society was restricting access to services for females.

Table 5.7 : Numerical breakdown of user participants

Transcripts	M: F ratio Transcripts	Adult users	Carers for adult users -all female	Parental transcripts	Age range of persons with impairment
27	16 female 11 male	19 male 3 female	2 wives 1 daughter	7 mothers 3 fathers 1 grandmother	5-70's

The data set achieved represented a diversity of socio-economic status, included urban and rural locations, male and female, a range of impairments, levels of severity and wide age range. All user participants were Muslim except for two adult males who were Hindu and this represented the societal make up well.

Providers of adult services were also predominantly male and reflected the visibility and dominance of males in the society generally. The caring role seen was exclusively female, although three fathers participated as the responsible party for their child and two fathers accompanied male children from a distance to access services. None of the adult female users were being cared for by males. All units offering services for children were headed by females. The opposite was true for adult projects where leadership was exclusively male.

5.1.9 Impact of Gender Stratification on the Education of Therapists

Observations around gender stratification suggested two areas for attention of relevance to therapist education. Services that aim to provide services for both genders equally must think carefully about the gender ratios in trainees to ensure sufficient female personnel are available to accommodate social norms operating.

Secondly the absence of female children from poorer socio-economic and rural backgrounds suggested that gender bias in access warrants further attention in service provision.

In reality all the professional courses (diploma and degree) were including more males than females in an approximate ratio of 2:1. The 'related healthcare worker' training was largely male for both Leprosy Physiotherapy Technicians and Community Rehabilitation Technicians. Community Handicap Disability Resource Persons who were all trained by a development organisation showed a more even gender balance. All developmental therapists trained in Bangladesh were female.

5.2 Section Two

5.2.1 Rationalisations Around Impairment

The spiritualisation of all of life's experiences in Islam, and the way in which beliefs around disability are a mixture of religious and cultural, were previously discussed in chapter two. It was also noted that the common construction of disability in Hindu belief systems in India tended to use individual model terms where impairment was linked to unavoidable punishment for wrongdoing.

Participants in this research adhered to a variety of causes and, sometimes contradictory beliefs for impairment. These were influenced in part by different levels of exposure to biomedical explanations imparted. The most frequent causal explanation given was that impairment was a punishment for some form of wrongdoing. Levels of education, socio-economic status, rural/urban locations and generational factors were significant factors in this belief. Older generations and participants in remote rural environments also tended to adhere to more traditional views of causation, especially that of attack by evil spirits. Younger and more educated participants accepted biomedical explanations more readily and often mixed these with religious explanations. There was clear evidence that beliefs were not static and continued to change towards understanding and accepting biological explanations as causative mechanisms. In almost all interviews with Muslim participants, the belief that Allah is the one who does everything and controls everyone was verbalised spontaneously at some point during the interview, for example:

FGP,CHDRP,U3 (Grandmother of boy with Cerebral Palsy) *'What a justice from Allah! The oldest son is in this condition...Why would he be in this situation if Allah didn't give it?!*

'*Taqwa*' (God consciousness) emerged regularly not only in relation to cause but also in relation to progress and outcome following intervention, for example:

FP,DipPT,U4 (Mother of male child with Cerebral Palsy) *'I used to cry in my namaz (prayer). "Why have you given me all these difficulties? What was my guilt (sin) to you?" Now he has brought me here and my child is improving'.*

M,BScPT,U2 *'It has been great for me. My leg has been cured. Now I can walk. I can move and earn. Allah has cured me with their (Physiotherapists) use'.*

MP,DT,U3 *'Let's see what Allah does. If he doesn't cure him, then there's nothing more we can do'.*

In the more rural locations there was more evidence that the influence of spirits (jinn) was considered to be a predominant causal factor. Beliefs in jinn were sometimes reinforced by explanations from spiritual or traditional healers. There was also evidence of change occurring:

M,CRT,U2 (Post stroke) *'I used to work at the (irrigation) pump machine at night time. That night, suddenly, I felt a hot blow of wind (something evil) and I fell down on one side'.*

FGP,CHDRP,U3 *'...We saw the kobirajs (traditional healers) and they said, "An evil spirit takes shelter in him and that's how it has happened"'*...

FGP,CHDRP,U3 *'... They (the locality) used to think it as a result of sin before and some said that evil took shelter in him but now they have changed their attitude since they (ADESH) started working in here. Now they (emphasised) know that it can happen to anyone'. (Smiles)*

In Nepal, Saul and Philips (1999) identified a continuum of constructions of disability linking three cosmologies namely a rural cosmology influenced by beliefs in ghosts, spirits and witchcraft; an urban cosmology influenced by religious beliefs and a cosmopolitan cosmology influenced by exposure to Western biomedical teachings. They note however that no cosmology is exclusive and individuals can hold different beliefs simultaneously. There appeared to be a roughly comparable continuum in Bangladesh. Although Bangladesh is a mainly Islamic society and family members based in urban locations frequently visit their rural homes, an urban/rural divide in opinion is evident with Western influences impacting urban, educated, more than rural, less educated, dwellers. The use of amulets and talismans to ward off evil

intentions was frequently evident in this study but appeared to be more common in rural communities.

5.2.2 Effects of Exposure to Biomedical Explanations

Frequently a biomedical explanation for impairment had been imparted to individuals during the course of successive visits to different medical and other personnel. As this occurred largely in the context of an institute, these encounters failed to impact the beliefs of wider family or community members. There was clear evidence that the plurality in views around causations of impairment could be both a comfort and a source of stress for participants in both rural and urban environments.

The following response came from a young woman who was injured when a wall she was building collapsed. Her exposure to alternative explanations for her paralysis came months after her injury when she was finally admitted to a rehabilitation centre for spinal injured patients.

***F,BSc,U3** 'They (in the village) say, "It's the result of a sin". They keep saying that all the time (smiling/shy)... Now from here, I hear that disability is not a curse!'*

During her time in the centre there had been little direct contact with other family members:

***F,BSc,U3** 'My brother came here three to three and a half months ago and since then... (Nobody came)... One of my uncles has a mobile and sometimes I talk to him on mobile...but they can't come.'*

This meant that the wider family and community members were not exposed to biomedical explanations and their views remained unchallenged. On return to the village, attitudinal barriers could be anticipated. This was very apparent in the research when rural homes were visited as the following account illustrates.

The young man had been involved in a road traffic accident three years previously when travelling home from a political rally, resulting in tetraplegia. The bus hit some branches of a tree and he and several others sitting on the roof of the bus, including one of his relatives, were knocked to the ground. He had spent six months in CRP where he was treated by professional (BSc) physiotherapists before returning to his village. A female Community Rehabilitation Technician who had been allocated to visit him intermittently took us to his home. On this occasion observations were very significant and were recorded in the field notes.

He was lying on a wooden bench on a mud track near to his home. This had been placed outside a small wooden shed, which was functioning as a shop. His relatives had done this in order to give him contact with people visiting the shop. He appeared to be severely depressed, a point completely ignored (if it was even recognised) by the female community worker.

His responses indicated that he had little, if any, support for his own, weakly stated, explanation for the cause of his impairment. Long silences punctuated this interview. His conversation was hesitant and he showed no change in facial expression throughout the interview which was cut short in response to the situation we met. Initially the research assistant gently asked what he thought was the cause for his impairment:

M,BSc,U1 ----- (Complete silence) -----

...’ It happened because I was hurt on my neck instantly after I was hit by the branch of tree. That’s the reason...(long pause)...They (the people locally) have different attitudes. Some say that the “evil wind” touched me or it happened in other ways. Some people say that ---- (long pause)... “May be he committed sin at some point and that’s why he’s suffering”’. (Long pause)

Main researcher *Has this been said about you?*

‘Yes ‘

Main researcher *Who says this sort of thing?*

M,BSc,U1 *‘People in neighbouring houses’.*

One of the villagers in the crowd that was gathering around us then commented to everyone that as he had not been cured even with treatment from the best centre in the country, the obvious conclusion must be that his condition was the result of sin. The speaker pointed out in support of his argument that his relative who was also hurt in the same accident had made a full recovery. No one in the crowd contested this conclusion including the CRT worker. The interview was curtailed at this point as further questioning in front of the crowds was considered to be unhelpful for the young man.

His distress appeared to be compounded by isolation and lack of emotional support. He had not been out of the small compound for over six months and the roads were muddy and narrow. To reach this young man’s home we had walked the last quarter of a mile on foot as the rickshaw was unable to go further. The extent to which attitudinal

barriers were influencing the lack of intervention to change this young man's situation was unknown. Simple adaptations to the physical environment to enable people with mobility limitations to move about more easily were not seen here or in any of the rural homes visited despite visits from community rehabilitation technicians who had all been trained in the country's only rehabilitation centre for people who were spinal injured.

The absence of environmental adaptations suggested a failure to implement standard advice received in the rehabilitation centre. The reason for failure was unclear as the CRT workers clearly had knowledge of what would help at a practical level. Observations suggested health workers engaged little with this aspect even though adaptations, for example, building a mud ramp could have been accomplished with minimal expense.

The female CRT worker in the example above had been allocated to visit this young man because of the proximity of her home. She appeared to interpret her role as dealing with selective aspects of his physical status only. She did not appear to interpret her role as addressing attitudinal or other issues negatively influencing a situation. As a young female allocated to deal with a young male she also appeared to be quite reticent to address physical issues such as bladder management or sacral pressure sores. Even though this young man reported that he had been lying on the wooden bench for around two hours when we arrived, the CRT made no comment and did not ask if she could check for his skin condition for pressure sores or offer any advice relating to these aspects of his physical management.

5.2.3 Impact of Findings for Professional Education and Training

The discussion raised by this and other situations like it, suggested to me that in addition to attention to gendered norms and quality of training, addressing prevailing belief systems and facilitating changes in the physical environment were major factors which could influence survival of people with severe impairment especially in rural areas.

Sheer and Groce (1988) suggested that societies treat individuals with impairments well or poorly based in part on culturally based beliefs about why impairment occurs. The possibility of correcting misbeliefs around causation of impairment by utilising

Islamic religious teaching in a positive way was previously discussed in chapter two with reference to on-going work in Bradford and Tower Hamlets projects in the UK. Participants' experiences reported in this study suggest that close attention to the impact of belief systems is warranted as an integral part of the education of physiotherapists and related healthcare workers and strategies need to emerge which are appropriate for collectivist societies.

The physical wellbeing of persons with high level spinal cord injury requires on-going daily assistance. For the young man we interviewed there appeared to be little support available apart from arrangements his family had made. His own stated expectation was that he would die within the next two years. It seemed that without the support he needed being in place, this was very likely.

Government inaction meant that little else other than actions provided by the CRT employed by CRP, an NGO, was likely to occur. The adequacy of interventions being provided was therefore a crucial factor if he was to survive. The inattention given to attitudinal pressures by the CRT worker was surprising. However, the difficulties he faced also indicated major structural failure to address his wider needs.

In Bangladesh a national disability action plan (which included schedules addressing Employment, Transport Facilities and Social Security allowances for disabled people) was drafted in 2002 and finalised in 2004 (in accordance with the Disability Welfare Act of 2001). However, no funding had been allocated for its implementation by 2005 and the plan was still awaiting approval in 2006 (Rahman 2006). Despite publicised commitments, the government was failing to address the basic needs of severely impaired adults. Constraints around funding available to NGOs meant that their potential to help in a material way was also limited.

This situation highlighted for me the importance of Baylies' (2002) criticism of the ICF namely that, as an instrument, it 'lacks a comprehensive tool for assessing the performance of governments, environments, social situations, capable of measuring lapses, obstructions and omissions as well as ameliorative and facilitative factors.'

Examples such as the one provided by this young man point to the need for education of practitioners to be informed by both cultural and structural analyses of disability in order to design interventions which are appropriate at both personal and social levels.

Priestley's (2003, p.16) maintains that personal life experiences are deeply embedded in the social. Thompson's (1997, p.20) suggested that discrimination also operates at three interconnected levels i.e. personal, cultural and structural levels. Both provide frameworks which could be used by informed professional and related healthcare workers to plan responses to both impairment and disability. Routinely considering aspects of disability through a wider lens (rather than simply at an individual level) would enable more comprehensive and strategic responses to emerge.

Iwama (2005) questioned the appropriateness of transfer of Western concepts of health defined along individualistic proclivities to societies which maintained collectivist value systems. Impacting the belief systems of the young man with tetraplegia in the example given above had clearly failed to change the way the community around him thought or acted towards him. This suggested that interventions needed to be at a collective community level rather than at an individual level if satisfactory outcomes were to be achieved. Jezewski and Sotnik's tabulation of personal characteristics of collectivist value systems identified the inseparable nature of an individual's existence from family and community (Chapter 2, Table 2.1). The young man's life was closely bound up with his family and community members. Rehabilitation interventions delivered at an individual level in an institute and followed up by occasional visits to his home in the community in the way seen above were wholly inadequate to address his needs.

5.2.4 The Impact of Failing to Address Community Beliefs

Participants reported dissonance and distress when faced with a multiplicity of other explanations from family and other community members. As in the situation described above, participants reported discrimination where an understanding of biomedical mechanisms resulting in permanent impairment had clearly failed to impact the community. There was also evidence in this study that when a community had been targeted effectively by health education campaigns that discrimination was reduced.

For one participant in Dhaka city, a teacher, the cause of her child's cerebral palsy was clear yet her view of causation differed greatly from reasons offered by people living in her parent's village home where a mixture of spiritual and traditional views prevailed.

FP,DT,U1 (Mother) 'Some people say, "This problem must be the result of a sin, may be you've cheated someone or maybe you've lied to someone. That's why

Allah has given you this punishment... Many in the village say so, "Now Allah is making you suffer."

'I know that there's a scientific reason behind everything. I had forceps delivery and the veins on her right side veins were damaged and that's why, (pause), but many don't understand it...'

Huda (2003) and Nahar (2006) reported the belief in Bangladesh that jinn (spirits) may be provoked to attack by particular behaviours, for example by a woman walking with her hair flowing. The teacher quoted above also reported this belief:

FP,DT,U1 *'In the evening when I let my hair free they (community members) say, "Did you not have one child like this? You're walking with open hair! That's why these things happen"'*

Generational conflicts previously noted (Grace 2008) were a further source of stress, particularly for mothers who were blamed for their child's impairment:

FP,DT,U1 *'My mother, my own mother! When I go home to visit her.....people come to see us and she says, "She was actually very fat and maybe that's why it happened". I say, "Even you say this!" She says, "I speak for your good". May be she speaks for my good but that sounds bad to me!'*

FP,DT,U1 *'My mother-in-law often says, "I've got seven children but I didn't have any of them disabled. Your first one is like that!"'*

Direct comments were also made to the following father in the urban area in which he lived. He cried as he related the discrimination he experienced towards his fourteen year old daughter:

M,BSc,U5 *'Many people are making many comments; "She'll never walk, there's no use treating her!" Or "It's better if she dies soon". I've heard these kinds of comments. Relatives of mine and neighbours have made the same comments'.*

Dealing with blame and negative opinions from family and community members added a significant challenge to all participants in addition to coping with, sometimes marked, physical difficulties related to the impairment. However participants appeared to be able, in some cases, to use their biomedical knowledge to refute accusations, for example,

CRT,U5 (Male) *'I know well if I'm a sinner or not! I understand my disease better. I slept less, I worked hard...I used to feel so tired after driving for so long. After fifteen days I had a stroke. I understood that it happened from my hard labour!'*

A very significant observation in this research was the contrasting experiences of the group of participants affected by leprosy who had been seen by Leprosy Physiotherapy Technicians in a rural project in the north of Bangladesh. All participants appeared to

be very well informed about the cause of leprosy and all, except the one female who participated, denied experiencing derogatory comments. When asked about the cause for her leprosy, the female participant was able to explain clearly how her diagnosis was reached:

***F,LepU1** '...I had a sore developing there. My husband tried many treatments for me but it did not heal. He worked in the mill nearby. They were miking, (i.e.using a loudspeaker to disseminate information)... They gave him a book...*

He said to me, "We've tried many treatments but it hasn't been cured. I think you've got this. You go to this clinic with this book on Monday." They saw my foot and matched that with the picture and told me that I had the same problem as was in the picture. They told me that I had leprosy and it was curable with medicine.'

The significant absence of debate around cause and reports of discrimination from community members, at least towards male participants, was an unexpected finding and stood in marked contrast to experiences recounted by people with other impairments. I had previously witnessed the marginalisation of people affected by leprosy in the south of the country where I had worked for four years and these findings prompted an enquiry from me to the Bangladeshi project manager concerning reasons for the low levels of stigma being reported.

I was informed that before this rural project began, an extensive health education campaign around leprosy targeting the community had been conducted. This had used several means of publicity including enlisting the support of imams and other leaders in the catchment area. The manager linked the low levels of stigma in the area to this rigorous campaign to dispel misbeliefs around leprosy. Croft and Croft (1999) previously identified that without a health education programme, levels of knowledge in Bangladesh about the cause and treatability of leprosy (and TB) was poor with correspondingly negative attitudes. The health education campaign appeared to be the decisive factor explaining the absence of negative attitudes as reported by the four male participants with leprosy. The main carer of an elderly man with significant impairments from leprosy in both hands (his eldest daughter), also attested to this. She was asked whether her knowledge about her father's disease had changed as she grew up and replied as follows:

FC,LepU5 *'Now I have a good knowledge (compared to when I was young). People thought that whoever got this disease would not survive...die, "Now you have good treatment and people get cured – that's what people say now"'*.

Research assistant: *'Have people made any bad comments (about your father)?'*

FCLePU5: *'No.'*

Withington (2006) noted however that despite the dramatic decrease in the last two decades, social problems and stigmatisation remains higher for women with leprosy than for men in Bangladesh. The experience of the female participant in this group concurred with this finding. She reported problems in her marriage which she linked to negative comments about her made to her husband :

F,LepU1 *(Female patient treated for leprosy)*

'Sometimes people say to my husband, "Your wife has got this disease. How can she run the family? Leave her... because of that, sometimes he tortures me....beats me up, sometimes doesn't take with me (engage in sexual relationships) or come to me"'.

5.2.5 Impact of Findings for Professional Education and Training

Addressing misbeliefs around leprosy in the community appeared to have a positive impact for people affected by this disease, particularly for men in this project. This suggested that attention to the wider community beliefs may reduce discrimination related to stigmatisation. The clear separation of disability and impairment provided in the social model of disability (discussed in chapter one) is of potential value here in relation to the education of personnel for this field, as it would enable activity related to the impairment and its effects to be clearly distinguished from those directed towards cultural (idealist) explanations of disability. As a teaching tool this clarity would enable the purpose of activities such as health education around leprosy to be made explicit. Finkelstein (1999) suggested that the construction of systematic forms of help according to the social model of disability would allow for the generation of new services and service provider workers known collectively as 'Professions Allied to the Community'. The activities of these workers would be directed towards enabling inclusion of people with all levels of ability. Addressing the cultural barriers to inclusion influenced the experiences of people affected by leprosy in a positive way. Thus targeting community misbeliefs around leprosy in this instance, illustrated the value of addressing the community as the source of disability.

A further issue relevant to the education of physiotherapists and related healthcare workers identified in these accounts, relates to the need to attend to gender differences in the experience of disability, particularly in strongly patriarchal societies such as Bangladesh. It is well recognised that disabled women and girls are subject to discrimination in multiple ways (United Nations Enable 2006). The extent to which this topic has been addressed in the education of professional physiotherapists and related healthcare workers is debatable.

The research findings above suggest that, in order to devise appropriate strategies for intervention, a raised awareness of these compounding issues is necessary. Thus, a wider understanding of rehabilitation than the limited view that follows on from a traditional rehabilitation paradigm, (which assumes a biomedical clinical orientation) is called for (Leavitt 1999, p.4). This also implies that an individual model of disability is an inadequate basis for understanding disability and its consequences, a criticism that has been raised by other authors (Groce and Sheer 1990; Hammell 2006; Swain et al 2003; Thompson 2001). This was discussed previously in chapter three, section two. Leavitt (1999, p.385) suggests that in acknowledging the social construction of disability, rehabilitation professionals then face a number of challenges. These include the development of the most appropriate service models and public policy to benefit disabled people.

The limited funding available to NGOs often means that economic assistance offered is selective and in this situation individual rehabilitation workers can do little. However, if rehabilitation workers understand the wider structural explanations for disability (including the recognition of government responsibility to actualise the rights of disabled people), this knowledge would help to move workers towards a proactive engagement with empowerment and capacity models of delivery (Habermas 1972) and move them away from illness and wellness models. Such a move would require a clear understanding of the rights of disabled people and a stronger engagement with social science and humanities.

5.3 Section Three

5.3.1 Gaining Access to Therapeutic Services

Getting any access to physiotherapeutic intervention was difficult for participants, because of the paucity of available information regarding what physiotherapy was and where it was available. The costs and difficulty of travel to centres offering physiotherapy services added greatly to problems faced in access, particularly for women. Participants had frequently accessed a number of different local sources of help before learning of the possibilities of therapeutic help. Most of the participants in rural areas (and many from urban areas) had accessed traditional or spiritual healers for their current problem. Only one father had firstly seen a medical doctor, who referred his son for diagnostic tests, which led to an early diagnosis. He was sceptical of the methods used by traditional healers.

MP,DT,U3 *'On the first visit he told us to have a brain X-Ray and found a defect in the brain. Will it work (get better) if the kobiraj breathes on him?'*

Others too were doubtful but sometimes still co-operated, for example the following mother had accessed a number of different healers and followed their instructions, but the man clearly had not:

FP,DipPT,U1 *'I went to someone who told me to touch a snake. After touching the snake I would be given a tabiz (spiritual symbol) which would cure my child. I didn't believe him and I was shaking with fear but still the mother in me made me touch the snake'.*

M,CRT,U5 *'Many of them came to me - they said I'd been touched by an evil wind and I needed cleaning, "You need to be beaten by the broom."...I didn't listen to them'.*

Others were clearly driven to find a cure at any cost and tried every avenue open to them concurrently or sequentially irrespective of whether they had faith in the methods used or not.

M,BSc,U5 *'...Homeopathy first, then kobiraj treatment along with tabiz, molom, (cream for massage). I never believed in these entirely still you can never tell who can help you. Along with that medical treatment, they (doctors) said she'd be ok soon'.*

Not all views on traditional healers were negative. One man insisted that the traditional healers help had benefitted him much more with holy oil and massage than the CRT worker who had only used exercise. This indicated that some traditional

healers were using physical methods that users found to be helpful. The man in question was unable to stand independently following a severe stroke.

There were several accounts of being financially cheated by different traditional healers and spending large amounts of family resources on contracts with traditional healers which promised full recovery. The depletion of scarce family resources added to the financial difficulties encountered in accessing medical and therapeutic services.

F,BSc,U3 (*Spinal cord injured female*) *'After the accident all the big trees were cut and sold off on my treatment...All the money has been spent on me. I've been to the kobiraj and spent about 5,000 taka on him. He said "I will make this patient walk in ten days only...'*

Participants learnt about therapeutic services through personal contacts or through development organisations that had included CHDRP workers.

FGP,CHDRP,U1 *'I heard from other people that they (NGO working in micro credit) wanted to discuss about the disabled people I thought, "I'll listen to what they say, it may benefit my grandson!"'*

FP,DipPT,U4 (*Female with disabled child*) *'One of my neighbours has a TV. He told me that there was an organisation called Pongu (CRP) working with the disabled children...After searching in many places, we finally found it.'*

Reports from users suggested that doctors appeared to know about the physiotherapy but did not give information about where this could be accessed. Some users claimed doctors actively withheld information from poorer patients, and others thought they withheld the information because they did not want to lose business for example,

M,CRT,U5 (Post stroke). *'I said, "Sir, what do I have to do at home?" He said, "Go home. Slowly you'll get cured". He didn't tell me if any exercise or walking would improve me'...*

'This is the condition of our doctors, they know but they neglect poor patients. They don't bother about telling them'.

Parents sometimes brought their children to doctors in the capital city, and some were clearly being referred onwards for developmental therapy. However, the information given to parents was sometimes misleading, for example:

MP,DevT,U3 *'I brought him to a clinic in Dhaka-to a doctor of the brain. He said, "If you go to that medical (Shishu) with your child, they'll show you exercise... If you're lucky your child will get cured from their care and treatment..."'.*

5.3.2 Information Needs in Service Users

Users interviewed showed variable understanding of conditions and were uniformly unclear about what could be expected from physical therapy. In hospital and clinic situations they placed great confidence in electrical equipment despite only receiving spurious benefit from these. Both parents and adults with impairment in this study appeared to view permanent impairment as an illness waiting to be cured, and assumed that children with cerebral palsy were suffering. It was noted in chapter one by Pfeiffer (1998) that an individual model of disability places an individual with impairment in a sick role and parents were looking to practitioners for a solution. Misplaced expectations around cure were common and often had not been corrected by practitioners. This father's response was typical:

MPDTU3 (*father of child with cerebral palsy*)

'I'm not so happy now. I've been coming here for four years and still he's not fully cured. How long shall I keep coming here?'

Reasons for this lack of understanding appeared to be a combination of a marked cultural reluctance to impart bad news, and observations sometimes suggested there was a lack of understanding in practitioners themselves. User reports of information received from doctors suggested that doctors, particularly those outside of the capital city, were largely uninformed about physiotherapy. This could have serious consequences for users, illustrated by this young woman who thought that it would be impossible for her to maintain her role as a housewife following her spinal cord injury.

FBSCu3 *'Doctors in Barishal told me that I'd never be able to walk again. After hearing that, I told him (i.e. her husband) to get married again. I didn't know I could maintain everything from the wheelchair. I've got everything after coming here this time... If I knew what I've known after coming here then probably I would not have told him to get married so easily...there's a lot of pain.'*

Participants frequently reported that doctors advised them only about medicine. In Bangladesh, opposing a superior's decisions or raising a question is considered bad manners (Rahman 2009). The impact of these cultural constraints meant that they were reluctant to question advice given, or seek further explanation. These behavioural factors coupled with a poor understanding of their condition contributed to an unending search for a cure.

It took several years for the following parent to establish that her daughter had severe brain damage and to develop a realistic set of expectations. Her report was typical of accounts heard of early consultations with doctors. Her consultations gave her few answers:

FPCHDRPU1 (*Mother of disabled girl*) *'When she was one year old and still couldn't lift her head...I used to see doctors at that time but they didn't understand...they used to give vitamin tablets'.*

Based on her own experiences she now thought that giving clear information from the beginning should be a priority of all medical workers and that improving knowledge base of all personnel was very important. Some other users did receive clear information and were self-managing their problems with exercise. This tended to be from the BSc group of physiotherapists who had good levels of knowledge in specific areas which they imparted.

M,BSc,U2 *'Doctors left me after writing a prescription. They didn't help me understand...physiotherapists helped me understand my problem..., I still continue my exercises and do them in the way they showed me '.*

On field trips to interview participants, three community rehabilitation technicians were observed with their patients whilst waiting to visit participants' homes. Observations suggested that the workers' understanding of the conditions they were treating appeared to be quite limited, for example one CRT applied the same basic repertoire of skills to every patient irrespective of wide variations in presentation. Patients, for their part, were unable to assess the levels of expertise they were receiving as workers did not reveal their status. It was notable that the rural clinic manager referred to the CRT workers as 'dactars' and this was a title workers liked to have.

Invitations to participants to express their opinion regarding interventions that might improve things for them were greeted with surprise. Workers consulted at every level were regarded as experts to whom users should defer and little was expected apart from treatment. The one clear exception to this was users seen by the female CHDRP worker in their homes. She was referred to as 'Aunty' by her own request and had insisted she should not be referred to as 'dactar'. She clearly had a more equal relationship with families visited. This factor is relevant to previous discussions around empowerment and medical domination in chapters 2 and 3.

These responses were consistent with social norms identified in Bangladesh by Maloney (1991) who noted that patterns of hierarchy extend into the workplace and society in general. They were also comparable to Pintu and Sahu's (2001) descriptions of Indian attitudes to healthcare providers where patients regarded their role as passive and to dispute recommendations by a provider was seen as impolite and inappropriate. They included the following:

MP,DT,U3 *'How do I tell you about that!! I'm no scientist or doctor ! "Sir dactar" can tell us what will be better'.*

M,CRT,U1 *'Such an important person like them talks to us....it's a lot for us. What else can we expect from them!?!... As she's got training in this area, whatever she'll do will be good for us'.*

F,CHDRP,U1 *'They'll be able to tell better if there's anything else or further treatment available. We depend on them. We don't understand that much'.*

This positioning as an inferior highlighted the role of expert that practitioners were often seen in. Because physiotherapy was a new form of therapy for most users they were unsure what to expect. Where improvement in a physical condition was quickly obtained there was a sincere expression of surprise that this had been achieved without medicine and a desire to spread awareness of physiotherapy widely:

M,BScPT,U2 *'It's amazing! It took only 15 days for me to stand up! It should develop more and should spread to other areas. Not only people from Savar should get better, all the people in Bangladesh should get better'.*

Although finding value in the therapeutic intervention was clouded by misunderstandings all participants valued the progress they saw or experienced in improvements of function and described these in various ways e.g.

M,CRT,U5 *'At that time my body was in a jam (stiff). It would take a long time for me to sit down and I'd have to stand up holding something. Now standing up, sitting down, feeding.....getting up and down on a rickshaw, moving around.....I can do them (myself)'.*

FGP,CHDRP,U1 (Grandmother-carer)

'At first he was totally lame; all his limbs were paralysed. For the last two years I've had this aunty (CHDRP). She used to exercise him and she also used to teach me before she'd leave... I've found a lot of benefit from that, good benefit. He couldn't walk before.....he could only slide on the ground'.

A small number of users mentioned their appreciation for the equipment, for example, an appropriate chair for a child that they had procured. However, a major part of satisfaction in users related to positive psychological support and hope that they had

received in and through these interventions. Same gender relationships in adults seem to be the most supportive and indeed essential for this to be achieved. All users specified personal qualities of sympathy and understanding as the most needed and most appreciated qualities in therapists. One father whose daughter was seen by diploma level physiotherapists stated this was the area that needed more attention. This aspect was possibly of enhanced value because of the prevailing climate of negative public attitudes.

FGP,CHDRP,U1 (Grandmother-carer) *'She's always encouraged me whenever she saw me upset and has given me hope that he'd get better'.*

M,LepU5 *'When I went to Dhanjhiri; they took care of me like their own brother...'*

M,BScU2 *'They were good. Doctors (physiotherapists) encouraged me. They told me that I would get cured. This is a big mental strength when the doctor is with you'.*

MP,DipPT,U5 *'..I think they should think about it (parent's psychology) more deeply. They should be much close, that's when it will be most effective'.*

Parents were especially sensitive to breaking social norms, and needed the therapist to be understanding when this happened. Fathers sought to avoid the possibility of this occurring, for example:

FP,CHDRP,U2 *'We're worried that she's a big girl now and she's peeing in front of you, ...Some people say, "She's grown up now.....still, she's peeing here (in front of people)!" They (therapists) should not have this kind of attitude, any of them. They should have a really good attitude and should have a softer heart'.*

FP,DT,U1 *'When I go to a wedding party, she and her father stay at home. "Leave it, I won't go. People will ask different questionsor she'll make mistakes"'.*

FP,CHDRP,U2 *'Once they advised from CRP to admit her in their school, but her father didn't let her go there because she can't express her toileting needs'.*

Mothers benefited from group therapy with children, gaining psychological support from female therapists and other mothers, which enabled them to deal with negative comments about their child. Fathers however appeared to be a group whose psychological needs and information needs often remained unaddressed.

FP,DT,U2 (Mother) *'I didn't understand anything before and used to get very upset. I used to cry in my house. Now, I come here and see many children having these problems. Now I don't listen to those comments'.*

FP,DT,U1 *'He (father) still hasn't been able to accept the situation. I can see a lot of children here and share my feelings, but he hasn't got anyone to share his feelings with'.*

FP,CHDRP,U2 *'Her father is very upset about her. He's got a very soft corner for her. When he's at home, he gives her a lot more time than me'.*

In contrast to mothers who were comfortable to become involved and to share with female therapists fathers attending therapy sessions with their child sat apart from the group and did not interact. Therapists also appeared to remain spatially distant and to interact much less with fathers. Lack of attention to fathers' needs for information had implications for both mothers and their children. Although fathers made decisions for the family and controlled the finance they were often least informed about their child's condition and what was realistic to expect.

FP,DT,U2 (Female parent) *'My husband didn't give me money to bring him here today. He said, "What's the benefit in going there? He hasn't improved at all. He's still the same. I can't spend any more money on him".'*

The pressing need in Bangladesh to educate fathers around impairment was highlighted by the report of one mother who arrived with her child at the mother and child care unit with an ultimatum from her husband; if the child wasn't cured on her return then her husband would find another wife.

5.3.3 Impact of Findings for Professional Education and Training

The situations encountered suggested that mothers with disabled children gained from group work in female led clinics in many ways but, because of gender norms, fathers were unable to benefit to the same extent. Specifically targeting fathers' needs and educating them about impairment using same gender relationships could, ironically, hold distinct advantages for mothers and disabled children in the long term. A situated response to the patriarchal nature of society and to the family and kinship systems operating is called for when devising intervention programmes in culturally appropriate and gender sensitive ways. Maas' (1997) suggested that CBR workers in Palestine required a knowledge of the community and its disabling practices. Her observations are relevant to workers intervening in the lives of disabled people in Bangladesh. It was clear in this study that, whilst some of the barriers disabled people faced were being addressed, others clearly were not. Solutions need to emerge which enable greater inclusion and counter socially oppressive practises that are embedded within communities. These include the need to find ways of facilitating access to good quality health and rehabilitation services.

Attention to giving clear and compassionate information to service users regarding the permanence of some types of impairment had been omitted for many participants. This may have indicated that workers themselves need to be better equipped with understanding and knowledge, calling for more attention to better training of healthcare workers, but it also pointed to the need for the development of communication skills. Transmission of accurate information in culturally sensitive ways would enable service users to make more informed choices.

It was not in question that users in this study appreciated improvements in physical status. Ghai (2002) writing in an Indian context, pointed to societal values including the valorisation of physical perfection as the reason behind the overwhelmingly negative assessment of persons with impairment. All participants in this study had clearly utilised a set of parameters based on their own and their community's notions of 'normal' and what constituted deviations from it. Loss in functional ability was linked to an inability to fulfil social roles and carried strong social sanction for all except the elderly. Participants in this study wanted help for the problems they had and sought this out with persistence. They were, however, (understandably) unable to assess the level of competence in various workers, which appeared to require much development in a number of instances, judging from my own background in physiotherapy,

Marginalisation and oppressive discriminatory practices were experienced by participants at personal, cultural and structural levels within this social context. In light of the intense subjective experiences reported, a very high value was placed on psychological support. Murphy et al (1988) claimed that rehabilitation establishments were ineffective in preparing people for the social conditions they faced, and there was evidence that this was also true, particularly when users were treated on an individual basis in institutes and returned to rural communities. Patterson and Hughes (2000) identified the tendency of rehabilitation professionals to objectify the body and ignore the subjective experiences of disabled people, and Hammell (2006) questioned the adequacy of a function-obsessed approach to rehabilitation. In this study, the lived experiences of disabled people related to issues at personal, cultural and structural levels, which were intertwined. The need for interventions which addressed needs at each of these levels was articulated, although expectations of different therapists related to users perceptions of them largely as types of medical

practitioners or ‘dactars’ primarily concerned with the body. Support and encouragement from with these personnel was highly valued. Ghai (2001, p.29), writing in India suggested that giving support towards the negotiation of positive identity should be routinely addressed as part of rehabilitation, and her suggestion appeared to be equally applicable in Bangladesh. However where interventions additionally began to address broader concerns e.g. CHDRP interventions around advocacy or help to secure loans, then, in line with claims by Davidson et al (1997), the service offered was arguably more effective as it was also directly addressing the wider spectrum of problems perceived by service users.

In summary, interventions which addressed impairment at personal and cultural levels enacted in the context of the local community were clearly helpful and enhanced service effectiveness. Questions around where responsibility lay to address the awareness of structural causes of disability resulting in poverty are presented in the next section.

5.4 Section Four

5.4.1 Perspectives Around Society’s Obligations to Disabled People

Coleridge (1993) noted that disabled people in developing countries often placed their need for income at the top of their list of priorities. The material impact of disability and the need to generate income was the dominant report of all participants except for two male participants who were in secure socio-economic positions and had relatively minor levels of impairment. The need for income was more acute for those already living in poverty prior to acquiring a significant impairment and dominated discussions around society’s obligations to them. Loss of income and extra expenses incurred around diagnosis and treatment plummeted many families even further into poverty. The main concern of disabled male participants was directly related to their role as providers for their family. Acquired impairment in males affected all members of the family including school attendance of children, which in Bangladesh involves a number of payments. One participant who had suffered a severe stroke and walked very slowly was interviewed outside a simple hut in which he was now living, was asked about the impact of this on his life:

***M,CRT,U5** ‘I’m fallen...a big loss in my life. I can’t earn. I can do nothing that I did before. I eat and lay down like a dead man...’*

'Since I became ill...one of my daughters was in class three and the other one in class five in school, they both are not going to school now... I was living in a better place...I rented a house. I had to come to this place...taking someone's pity. I live here free...I've got a lot of difficulties...'

The following participant was interviewed sitting on his bed in a one roomed mud building. He was now unable to stand without support several months after his stroke. The major concern he also expressed was the loss of his job and the loss of earnings had on his family. He had four children around him. One was absorbed in playing with a rat under the bed throughout his father's interview.

M,CRT,U2 *'My children don't get adequate food or clothing. This is a big problem now. If they get food and clothing properly, then my problems are solved a lot'.*

Dubes and Charowa's (2005) contention that poverty is a symptom of imbedded structural imbalances, and results from limited or no access to basic infrastructure and services needed to ensure sustainable livelihoods was true for many participants both before and after onset of impairment. Becoming physically impaired served only to increase marginalisation of people already living in chronic poverty. Yeo's (2006) representation using interlocking circles depicting features of poverty, disability and marginalisation (Chapter two, Fig 2.2) typified many participants in this study. Two younger male participants with leprosy asked for help to find employment. Two men reported that their wives were now working as servants in order to secure an income for the family and one elderly participant affected by leprosy mentioned begging as a means of survival.

For females the loss of ability to perform household tasks expected of them was a major worry and brought real threats of abandonment. The labour intensive role of the females in poor rural households heightened the vulnerability of their position.

The one specialist rehabilitation centre for people with spinal injuries in Bangladesh did have a limited number of training schemes aimed at enabling disabled women to generate an income. However, top down practices and professional dominance meant that these were mainly prescriptive rather than empowering. One female participant was keen to devise a plan to generate income based on her pre-existing skills and knowledge but described how her requests had been over-ruled by professional therapists dealing with her. Although she was disappointed she complied with their decisions.

F,BSc,U4 *'I said to them, "Look, I know nursery and it brings a lot of money. Now teach me how I can do it from a wheel chair". They said, "You should learn sewing rather than that and if you can, do some of that nursery along with that." They prioritised more on sewing..'*

For parents or carers of disabled children, securing the future well being of their children was linked to concern for their financial security and a desire for them to receive a simple vocational training. Their further area of concern was school admission. Only one child out of seven represented in this study attended school, and this had been achieved following the intervention of a CHDRP worker.

FGP,CHDRP,U3 *'We couldn't admit him. That aunty admitted him in the school. They didn't want to admit him so they (ADESH) went there and talked to them about that and admitted him in the school finally.'*

Access to school for disabled children in Bangladesh is extremely limited. According to Rahman (2006) of an estimated 1.6 million disabled children within the primary school age less than 5000 are enrolled in special and integrated education programmes. One of the reasons stated for this is that education for disabled children is under the purview of the Ministry of Social Welfare, which plays no part in the activities of two ministries of education which are striving to meet the millennium development goal of universal primary education.

5.4.2 Knowledge of Rights in Users

An area explored with all users was their knowledge of rights and responsibilities of society towards its disabled members. There was no evidence that participants had been taught about their rights in the course of contact with therapists as knowledge of the rights of disabled people was almost completely absent. Two females said they had seen something on television about rights for disabled people, and one male participant who worked in a government hospital knew that the quota allocation for employment of disabled people in government sector jobs was not happening. One father, a farmer, had no understanding of the notion of rights:

Researcher: *'Do you know anything about the rights of this type of children?'*

MP,DT,U3 (Farmer with five children) *'What is "right"?' '*

Researcher *'That this type of child would go to school, or would receive support from the government? Have you heard anything like that?'*

MP,DT,U3 *'No, I haven't heard anything like that.'*

Researcher *'Have they told you anything from here?'*

MP,DT,U3 'No'.

We informed one female participant during the interview that the government now had legislation around the rights of disabled people. This was totally new to her despite a stay of several months in the rehabilitation centre. She felt however that the voice of disabled women would carry little weight in claiming their rights, and insisted that healthcare workers could, and should, use the influence of their status to lobby for change.

F,BScPT,U3 *'You, those who are working with us, if you all speak about it, then it may happen in future'.*

5.4.3 Government Responsibilities

Despite widespread ignorance about rights in users, almost all users could readily identify changes would make a significant difference to their lives, and they all felt the government had a responsibility to act for them. There was, however, a marked lack of faith in the government's interest or willingness to act, accompanied by sense of powerlessness for them as individuals. The response from the young man with tetraplegia who had been returning from a political rally when he was injured typified this :

M,BScPT,U1 *'For three years I've been suffering since the accident but they (the government) don't even take any notice of us.*

' My demand is that they take some responsibility for the survival of the people like me, that's all'.

The Department of Social Security in Bangladesh issues a monthly allowance for aged people and widows, and claims that disabled people are prioritised during selection of these beneficiary groups. According to Rahman (2006), in most cases local political leaders use these schemes amongst their 'vote banks' so disabled people lose out. One very elderly man who was partially sighted and had a number of other impairments had ceased to receive the small amount of support allocated to the very old, and he gave the following account:

M,LepU5 *'They've got a new chairman now. They (government) used to give me 100 taka every month (approximately £1) as an elderly support fund from the government, but the new chairman stopped it as he's from a different political party and I gave my vote to his opposition..''*

This lack of confidence in the government's commitment to take action on behalf of disabled people was a recurrent theme pervading all user interviews.

Users were asked to identify specific changes that they thought would be significantly helpful to them. For adult males acquiring impairments, the main view expressed was to help with means to income generate. The suggestions included re-training according to physical ability level, and providing loans to enable them to begin a small business from their home. An alternative suggestion was to offer training to a member of the family. For children the main consideration was providing access to schools and providing treatment centres that were local and more easily accessible for parents.

FP,DipPT,U4 *'If my child can go to school, if he can mix with other children and play and if the children can have fun together that would be my happiness '.*

MP,DT,U3 *'If the government starts a treatment centre in their village or in my village, then it would have been better. We now travel 20-25 miles but if it was in my thana... If they want to go even closer to poor people, they can open it at union (local) level'.*

A further request concerned financial help for a disabled child after the death of the parents, particularly for poorer families. Suggestions including the provision of a child support scheme, or some training for the child that would enable them to generate an income.

FP,DipPT,U4 *'Maybe if the government helps him financially, and then maybe someone (a paid carer) will look after him'.*

FP,CHDRP,U2 *'I'd be happy if they arranged something so that she can do something in future to run her life.....so that they train her on something (vocational training)'.*

The source of help for disabled people in the villages was non-government organisations. There was recognition amongst several users that the resources of non-government organisations were limited, and that government initiatives were needed to provide more access to rehabilitation centres. Other participants highlighted the need for income support for families where this had been lost through injury, but were equally sceptical about the possibility of changes becoming a reality.

M,DipPT,U2 *'The social welfare and treatment services should be extended to grass root level. But still that's a dream for us. Will it really happen in Bangladesh?'*

One well-educated businessman had benefited greatly from the physiotherapy intervention he had received in CRP and felt that the services should be more widely available. He expressed the view that the government needed to take responsibility to

train more personnel and provide better access to services. In his view political will was lacking and people needed to become politically active and demand change:

M,BScPT,U2 'Government can do a lot if he wants. They can train more people and can establish more training courses in different places....Demand to the government should be published in all the newspapers, TV, and then the government will become aware. If the public go there and demand, then the government is bound to give that.'

5.4.4 Impact of Findings for Professional Education and Training

Most users' knowledge about the rights of disabled people was completely absent, sometimes with no understanding of the concept. The absence of any coverage of rights from therapists they had been in contact with, sometimes for several years, suggested that this element was not given emphasis in the therapists preparations and role. The one exception to this was CHDRPs whose training in CDD included a specific focus on rights and inclusion. One user seen by a CHDRP worker related how this worker had succeeded in gaining admission to school for her disabled grandson following the family's experience of refusal. (See Appendix three gives more details of the emphases of the training organisation CDD)

Several situations were encountered throughout the user interviews where knowledge of the rights of disabled people, if present, could have begun a process of empowerment. It was possible to link disabled people with the growing network of disabled people's organisations. This may have resulted in a raised awareness of marginalisation and would have strengthened collective attempts being made to address this. Groups such as the National Forum of Organisations Working with the Disabled (NFOWD) were actively linking groups together and promoting the rights and interests of disabled persons.

Needs most commonly identified by users related to poverty. Users recognised that non-governmental organisations had limited resources to meet the needs of disabled people and almost all thought that much more could be done by government to address their needs. Some stated that collective action was needed to lobby the government for change. They listed a number of changes they felt were needed: these included financial help for families plunged into extreme poverty because of the loss of income following impairment, training schemes to allow newly disabled people to retrain and loans or grant systems are to enable them and help meet costs of on-going

support. Educational provision for disabled children was considered to be essential. They stated that services need to be within reach of users. Home-based services were appreciated, particularly by women, given the various constraints around travel they experienced. Information about therapeutic services needed to be disseminated widely. The need to train more resource personnel and establish more rehabilitation centres in districts around the country was also identified. Groups such as professionals were considered to be politically strong and able to speak out in support of disabled people because of their enhanced knowledge and social status.

Hammell (2006) and suggested that therapists play an active role in maintaining and perpetuating disabling environments or an active role in changing them. A lack of awareness of rights, and inattention to socio-cultural domains of disability, meant interventions at a personal level although valuable were limited in their impact (This was previously discussed in Section 3.2.1). The findings suggested that for workers to be effective a considered response was needed towards the socio-cultural aspects of disability.

The traditional rehabilitation paradigm assumed in physiotherapy often adopts a biological clinical orientation and intervenes at a personal level only. Evidence emerging from participants in this research suggests that the lived experience of disability is a complex mixture of experiences impacted by individual and social factors which are variously described. The different models of disability were discussed in chapter one and the complexity of disability was presented as a typology by Priestley (2003) who suggested that it might be more appropriate to view theoretical approaches as overlapping areas rather than discreet conceptual boxes. Correctly theorising disability in the training of workers enables justifiable responses to emerge which do then address issues important to disabled people and thus, enhance service effectiveness. Several authors noted in chapter four, section 4.1.0, emphasised the link between service quality and the need to satisfy problems perceived by users (Davidson et al 1997; Coring 1999; Cuganese et al 1997). Problems of disability need to be clearly understood by workers in this field and therefore theory which incorporates an understanding of different conceptual models becomes an important consideration. Barnes and Mercer (2003) pointed out that debates using concepts developed in English-speaking countries defy easy translation into other languages and cultures

where ways of perceiving an individual differ and therefore it is important that the understanding of disability emerges from the local context. Different practitioner models were also discussed in chapter three (section 3.1.4) and appropriate choices of practitioner model need to emerge that enable user needs to be adequately addressed. The failure of training and education to adopt a capacity model of practice (discussed in section 3.1.4) had negative consequences for users in this study and in some respects represented a missed opportunity.

Participants in this study indicated that whilst impairment needs were important, rehabilitation needs to become orientated to socio-cultural domains, including an appreciation of material conditions and social relations comprising culture, religion, gender, economic status and importantly, the political environment. Family and kinship systems and patterns of hierarchy and deference were themes that occurred frequently. Conformity to social norms was an area of sensitivity. The accessibility of services and attention to information needs were also seen as important in moderating user experiences.

Gender issues raised suggested that more attention needs to be directed to gender ratios in student intakes in order to provide gender sensitive services. Considerations around equal access also need to consider a positive discrimination towards facilitating greater access for female populations in lower socio-economic groups in service delivery. The multiplicity of factors impacting the lived experience of disability can also be adequately theorised by identifying the outworking of discrimination contained in participants' accounts, considering this at personal, cultural and structural levels.

A possible outworking of the messages emerging for education from participant perspectives is shown in Table 5.8 utilising Priestley's (1998) fourfold typology of disability (discussed in chapter one, Section 1.5.1).

Table 5.8 : Lived experiences of disability and implications for professional physiotherapy education and training of related healthcare workers

Impacts on the lived experience of disability reported by participants.	Explanation of disability	Implication for professional and healthcare worker education
Religious Beliefs: Impairment is a punishment. Traditional Beliefs: impairment due to disturbance of jinn. Gender considerations	Social model (idealist) Culture	Attention needs to be given to devise strategies to correct misbeliefs at a family and community level. Opinion leaders need to be identified, and their support enlisted. Biomedical explanations for impairment should be given in clear and compassionate ways. The impact of a plurality of providers needs to be acknowledged and addressed.
Impairment and its effects Functional loss	Individual Model (materialist) Biology	Therapeutic input needs to relate to functional goals in the living environment as identified by users. Attention is needed to the supply of appropriate appliances and environmental adaptations. Information needs should be addressed in gender sensitive ways.
Psychological and identity issues Gender issues Generational conflicts	Individual Model, (idealist) Psychological	Prioritise psychological support to empower and strengthen positive identities in persons with impairment. Use group work for females and children. Attend to gendered social roles and family and kinship systems e.g. replacing notion of user as an individual to 'family and kinship unit' as appropriate.
Structural failures to actualise rights. Poverty Marginalisation Gender issues	Social model (materialist) Structure	Teach rights-based approach to intervention. Address institutional and environmental barriers to education and employment. Support disability rights movement and lobby groups. Incorporate attention to gender stratification in all activities.

5.4.5 Chapter Five Conclusion

A number of messages relating to education and training of various groups of workers could be identified in the data. These messages related to explanatory models of disability, practitioner models and relationships with users, accessibility of services, gender and issues related to socio-cultural domains.

Users had been seen by at least one of six types of workers, all of whom gave interventions which included physiotherapy. Reports from participants in this study indicated that disability was experienced at several overlapping levels. Interventions from physiotherapists and related healthcare workers at an individual level were valued at a physical and particularly at a psychological level. However interventions which addressed the wider aspects of user experience frequently reported could be identified in user accounts. Powerlessness in users was a specific feature which called for attention. Service user accounts suggested that a rights-based approach using a

capacity or related practitioner model (Sections 3.1.4 and 3.1.5) was needed to guide interventions from different workers. Findings suggested that more community based interventions needed to be developed to overcome barriers to accessing services. The impact of institute-based services although valuable and necessary in acute care was inadequate in the longer term. The collectivist nature of the society suggested that individual approaches frequently provided in institutes had a limited impact in the lives of disabled people. Considering disability at personal, cultural and structural levels would enable appropriate strategies for intervention to be devised at each level. Although boundaries for intervention are often shaped by local factors and constrained by available project funding conceptual changes discussed would facilitate better alignment of service provision with articulated needs of service users.

The following three chapters examine perceptions of different groups of workers around user needs, and levels of congruency of interventions with needs identified by users.

Chapter Six

6. SINGLE IMPAIRMENT GROUPS

6.0 Introduction

Chapter Six will report on initiatives to train two groups of workers around the needs of single impairment groups, namely people with leprosy and children with developmental problems, and identify perceptions these workers have around the needs of disabled people and roles they perform as Community Based Rehabilitation workers. On the basis of previous findings the chapter will attempt to identify the congruency of the two approaches with perceived needs of users.

Leprosy physiotherapy technician training was introduced into Bangladesh in 1991. Developmental Therapist training has occurred informally since the 1990s. A formal course has been accredited in Bangladesh. At the time of data collection plans were being made for this to begin utilising existing links with therapists in the Institute of Child Health in London who have previously taught developmental therapists on a voluntary informal basis. The background for both these initiatives was presented in chapter three (Sections 3.3.3 - 3.3.5).

The chapter is divided into two sections reporting firstly on developmental therapists and secondly on Leprosy Physiotherapy Technicians in Bangladesh. For both groups, workers' perceptions of user needs is given and an analysis of their roles. The strengths and weaknesses of training these types of workers are discussed in relation to findings presented in the previous chapter. A chapter conclusion is then drawn.

6.1 Section One

6.1.1 Developmental Therapists: Backgrounds and Work Locations

Both institutes in which Developmental Therapists were interviewed were in the capital city and were part of a larger non-governmental organisation, Bangladesh Protibondi Foundation, i.e. 'Foundation for the Developmentally Disabled' (See Appendix 8 for details). Three Developmental therapists were interviewed in the first institute, Kalyani Special School for the Disabled. This was housed in very cramped but functioning four-storey building located in a narrow road in a busy commercial area of

the city. The school was described as a 'Special School for Children with Cognitive Difficulties'. There was a small unit for children with Cerebral Palsy in addition to several classrooms and a skills training area. A further two interviews took place in the Shishu Bikash Clinic (Child Development Clinic) housed in a small unit established on the first floor as part of the National Hospital for Children located near the Parliament building. The close working connections of the two organisations was clear and well established.

The work of the child development clinic centred on screening, medical and therapeutic interventions, counselling and case conferences using a multi-disciplinary team. A further unique feature of the organisation was the use of a Distance Training Package Programme which utilised pictures to teach illiterate parents how to progress a child's development. Children assessed in the child development clinic were occasionally admitted to the school, however places here were limited and a fee was required. The wider work of the organisation included Community-Based Rehabilitation (CBR) work and the education of children in rural communities. This meant that staff on both sites were linked to a wider team of workers, which included those connected with a rural multipurpose team and CBR programmes in six locations.

Both buildings in Dhaka were difficult to access with a number of flights of stairs. Building maintenance was poor and the rooms were drab. However, the areas where children received therapy in both buildings contained a number of toys and small items of equipment, very typical of Western physiotherapy departments. The organisation lacked resources and funding. 'Inadequate premises' was mentioned as a difficulty in both locations. The Child Development Clinic functioned completely separately to the physiotherapy department of the hospital and there was little communication between the two.

All the developmental therapists were female. All had been personally approached to join the organisation and one mentioned working initially for several months with no salary before being invited to apply for a paid post. Training had been delivered by various different visiting foreign professionals including occupational therapists, physiotherapists and speech and language therapists, and psychologists from Canada, UK, New Zealand and other countries. The length of training courses ranged from one day to several months and spanned a variable number of years. Four out of five

developmental therapists interviewed held a masters degree but none held a qualification as a developmental therapist, as a formally accredited course was yet to commence in Bangladesh. Their awards were in various subjects including psychology, nutrition and special education. Two developmental therapists had received intensive training and supervision from the same foreigner for six months. Three others had supplemented their training by attending other related courses. One had trained further in India and one had studied in Boston, USA for several months.

6.1.2 Roles of Developmental Therapists

In both locations there were opportunities to observe therapists working with children. Two of the school-based developmental therapists had taken part in collecting research data in rural settings by visiting families with disabled children. They drew upon this and on their own personal experiences of life in relating accounts of their interaction with parents. All therapists interviewed demonstrated empathy and concern for the mothers and frequently talked about their attempts to develop supportive relationships with the families. They were all aware of the high levels of distress in families newly arriving and they prioritised the building of supportive relationships:

***DT2 (School)** 'At first I observe the parents. They need to be taken care of. They need mental support.You know, most of the parents come here crying and crying'.*

When asked if they worked with both parents, all indicated that they did, but more particularly with the mothers. They also indicated that positive changes occurred over time, as the mothers mixed with the group, for example:

***DT1 (School)** 'At first, I introduce the new mother to one of the other mothers. ...Within two or three days the new mother looks cheerful, she's talking, she loves talking to other mothers and to me, I explain things to her'.*

All therapists mentioned the family pressures on mothers and the difficulty for the mothers to work on exercising a child, especially in rural locations where physical demands on mothers was high and their own physical condition was often poor.

***DT2 (School)** 'In the village the wife will work all day long. They're in great misery. They can neither eat properly, nor rest properly. There's nothing for them, only work and work... Every year they're having new children...they're very unhealthy'...*

'...If she doesn't work, there will be a quarrel with the mother-in-law and sister-in-law. Does she work or does she exercise her child?'

They felt that this pressure was less in wealthier households where there was a greater understanding of the purpose and value of therapy and 'aiyas' (maid servants) commonly performed most of the household tasks. One therapist offered a solution to this problem by pointing to the need to involve and educate the family, especially other female members. She referred to appealing to the high value Bangladeshi families placed on the child, in order to elicit help for the mother with the disabled child, from other (female) members of the household.

DT2 (School) *'What I think is necessary.....we have to involve every single member of the family with this. When mum can't do it, mother-in-law or sister-in-law can do it. They may not like the mum but they do like the child. This is true. This is the tragedy in Bangladeshi families.'*

The same developmental therapist recognised that the more senior members of the family were very influential and more likely to believe in traditional practitioners than medical based services. She reported that beliefs were changing in younger generations and this would lead eventually to a gradual lessening of the use of these practitioners.

DT2 (School) *'We're in the 21st century! Still, people in the village seem to be very dependent on the kobirajs and Jharr-fook (whipping, blowing)! Some have been seen taking both Jharr-fook and medical treatment together. ...Because the grandmothers trust in Jharr-fook.'*

'Allah forgive me! If that generation die...if that generation is gone from the world...I think this will reduce a lot. I think this is already reducing. Twenty years back it was severe.'

Her own personal experiences as a parent caught up in generation conflicts helped her to understand the pressures on families to utilise traditional treatments and she advised parents accordingly.

DT2 (School) *'Once my mother-in-law became very ill and my family brought her here (to Dhaka). We admitted her in Bangladesh Medical through a lot of difficulties. She was on a saline...so sick. Still, in this situation, she kept saying, "There is man in the village that I trust. Bring him here".'*

'We had to bring him here; not because we believed in him...just for her mental satisfaction. Family members say, "We'll have to do whatever she wants as long as she survives. We can't disrespect her or show her disobedience".'

Her account was distinctive in that her personal background and exposure to the difficulties in family life in rural situations and pressures from family and kinship

systems, equipped her with an understanding and empathy which she clearly applied in her work.

DT2 (School) *'This is the situation in Bangladesh! We're educated and this is the situation in my family. This will be even worse in an uneducated family'.*

'...You know, some use so many metal things on them.....Talisman, signs.... I say, "Ok, you keep them but don't forget to do the exercises. Keep those going."...Day by day this will decrease,I'm hopeful about that'.

A further observation of rural attitudes was expressed by one of the therapists who had participated in research in the villages. She indicated that learning difficulties were seen as less problematic than physical difficulties:

DT1 (School) *'Actually, in the village people are not very worried about their mentally handicapped children. When the children go to school, they don't get any profit from that. If they stay at home, they can help their mothers with household tasks. So mothers get help from them'.*

'... but I've seen that those who have physical problems are very big burdens for the mother. They need to carry them, feed them, they have to move around with them...so it's a big difficulty for them'.

The distinctive feature in the child development unit (where there was minimal reported experience of working in village areas with families) was the strong medical emphasis, and Western approach with frequent mention of foreign therapists. One developmental therapist strongly maintained that the multi-disciplinary approach was very comprehensive and 'missed nothing'. She compared that to the 'people downstairs' (referring to the hospital's physiotherapy department) who sent the child away after giving only physiotherapy.

DT3 (Child development unit) *'We work with multi-disciplinary approach. We're not only providing physiotherapy here, we're looking at a child's total (problem).....Shishu Bikash refers to a child's physio, occupational, speech, language and communication, cognition...everything...we deal with everything'.*

The female director of the unit who had studied in London and had arranged the training was strongly convinced that developmental therapists were more cost effective than the use of separate professions. In her opinion it was a more appropriate approach in low resourced contexts such as Bangladesh. In the special school the inclusion of education was naturally emphasised and there was more focus on the transfer of knowledge and handling skills to the parents than providing 'treatment'. This was justified by one therapist in the following way:

DT1 (School) 'Parents are the first (to deal with)...because the parents should be aware...you know... If you can teach the parents occupational therapy, special education...everything...that will be most effective because the children stay with them most of the time. So, my emphasis is to teach the parents how to work with them, how to handle them, how to spend the whole day'.

6.1.3 Relationships with Medical Professionals

Views concerning doctors varied amongst developmental therapists. In the child developmental unit therapists reported good experiences of working in a multi-disciplinary team alongside doctors who appreciated their input. There was clear evidence that therapists assessed newly attending children in a team of three consisting of doctor, psychologist and a development therapist.

DT4 (Child development unit) 'Doctors are very good. They take such a long time and have so much patience to see a child... Doctors actually can't do without us...I mean they have a really good attitude towards us'.

Therapists in the school related parents' reports of their experiences of taking their children to doctors elsewhere. The scenario they described was a brief consultation where parents were handed prescriptions. They were rarely given an explanation of the problem, they received vague or no instructions about what to do, and doctors appeared to have little knowledge about physiotherapy. They felt they needed time to talk but this opportunity was not given.

DT2 (School) 'Parents say, "Doctors write, give vitamins, injection ...take her home", and it's all finished there..They say, "Doctors don't even give me time to talk. I can't even talk to them!" '.

A further explanation offered for doctors' frequent failure to refer children to physiotherapy was to guard their own levels of financial remuneration.

DT2 (School) 'They don't want to tell...they know about physiotherapy but they don't want to tell the patients for fear that they'll leave them. They think, "This patient will leave me and I won't get money from her anymore". I think this is the fact'.

The importance given to developing a trusting and supportive working relationship with mothers was mentioned repeatedly in both institutes. During practical sessions observed with the children in both institutes where fathers had accompanied the child, fathers remained spatially distant, standing or sitting at the side of the room. They were noticeably less interactive in the whole process, taking an observatory rather than a participatory role. Although this feature was in keeping with cultural norms, it

also meant there was less communication and exchange of important information with fathers.

In keeping with arrangements we arrived in the Child Development Centre at 8.00am as instructed, but despite claims of being 'very busy' neither staff nor parents with children arrived until after 9.30am. It was likely that getting to the clinic, which was located in a central part of the city, on overcrowded buses was very difficult with young children. Costs of travel were also prohibitive for many and cultural restrictions on travel for unaccompanied women further restricted mothers who may have wanted to attend. All developmental therapists interviewed were aware of the difficulties in accessing their services.

6.1.4 Approaches to Treatment

All the development therapists knew about a one-year course that was awaiting implementation. The more experienced ones were ambivalent about wanting to do this, apart from the thought of getting a certificate which would validate their role as 'qualified' developmental therapists. Some had clearly already achieved good clinical standards and related the input they had had from foreign, highly qualified professionals including physiotherapists, occupational therapists, speech and language therapists and psychologists. The absence of a certificate meant that they felt that they were not really qualified and they expressed a lack of confidence in themselves. This was irksome for them, particularly when faced with the recent appearance of young BSc students on placement who tended to treat them with a lack of respect.

Researcher *'You've already got a degree?'*

DT1 (School) *'Yes, Master's. Gillian gave us a one year training...how to work with Cerebral Palsy children. And, I've told you...from 2002-2003, I'd done a course in Boston in Children and Handicap. Often cerebral palsy children come with multiple handicaps...hearing impaired, Down syndrome....you know'.*

'...sometimes I get depressed that I don't have any academic qualification. If you call me a Developmental Therapist, I feel shy inside because academically I'm not qualified. Why should you call me a Developmental Therapist? It makes me depressed. So, I think, maybe I need an academic degree on that'.

Another of the therapists commented on her 'package' of training which was very different.

DT3 (Child development unit) *'... it was not like a course. They left after one week training and then they came here again for a follow up after a year and*

evaluated us. Then, Patricia came and we received 'comprehensive'...she trained us on everything...hearing, vision, cognitive...she taught us everything. She ran seven days workshop... in a row. Then she came back again and did a follow-up to know how we were doing. We were even sent on training (outside the country). Almost all of us received one to one and a half month training in UK'.

The least experienced developmental therapist was keen to learn in order to do a better job with greater level of understanding.

DT5 (School) *'...I think we need more training and better training. I myself lack in many areas. For example, we do an exercise keeping the child in prone position and people ask us "Sister, why do you do it this way? What's the benefit of doing that?" We can't directly say which muscle is getting benefited or which muscle is getting stimulated...it would have been better if we had some more training and even better training'.*

The lack of standardisation in their training was reflected in the diversity of opinions regarding cerebral palsy and what they could offer. Quite different stances were held by therapists working in the same room regarding advice to parents. This appeared to reflect different training experiences they had had in various countries. One therapist who had spent time studying in America was distinctive in her insistence on de-medicalising interventions. She reported meeting resistance in BSc students when she insisted they do the same:

DT1 (School) *'The student (BSc) assessed, wrote down the name and wrote down the disease name and then I stopped him, "No, we don't use these words. You must stop using those words 'client' or 'patient' about our excellent children".'*

'Even when we were talking, mums were so worried and concerned to hear those words. When we say, "children", the mums are so gentle and nice. But when they hear these words they looked so worried. So, you see the impact of words! They've never heard those words. I was really surprised that day and requested them not to use those words anymore'.

She explained how she taught parents to deal with comments about their child by strongly resisting the idea that a child's difference was a problem:

DT1 (School) *'If anyone says anything, you have to say, "No, my child hasn't got a problem" because your child hasn't got a problem. I myself can't do anything....I can't cook...I can't write a good report. I myself have got so many disabilities but my disabilities are not visible. People can see the disabilities on a Cerebral Palsy child but they can't see my disabilities. That's the only difference. Your child is perfect. He doesn't have any problem ...He's a Cerebral Palsy child...makes a few mistakes'.*

Her colleague working alongside her in the same role was more comfortable with a more medicalised approach. She had been trained in India for six months and used the

notion of “treatment” readily and pointed out to parents exactly where the child was delayed compared with standardised developmental milestones:

***DT2** (School) ‘I want them to understand, I say, “You yourself can understand how delayed your child is compared to other children. What a child of his age can do...your child can’t do that. So, you have to do some work on him. You have to do this and this. If you do this, slowly your child will be developed and this delay will be reduced”.’*

One of their counterparts, in the child development centre expressed the idea that ‘cure’ was possible provided enough ‘treatment’ was administered for a sufficient length of time.

***DT3** (Child development unit) ‘It’s a good side that I’m able to cure this type of children through my treatment. When I’ve seen many patients getting cured in my hands...I’ve felt really good, thinking, “I’m doing this and the child is getting cured!”*

Her interview was interrupted a number of times by the entry of one of her colleagues who appeared quite anxious to hear what she was saying, at times correcting the details being reported. Her colleague sometimes displayed a tendency to identify a child solely in terms of their impairment:

***DT4** (Child development unit) ‘When a child enters here we observe what type of child he is. We can see how a “low vision” walks in and we can also understand just from watching that a child has got stiff hands and legs...’*

None of the therapists identified non-clinical subjects as areas needing more attention. The subject of rights raised little interest from developmental therapists. One knew that the government publicised its belief in equal rights from time to time but expressed a lack of confidence that this rhetoric would ever be fulfilled. Another didn’t understand the question when asked if parents knew anything about the rights of their children. After it had been explained more fully she said the subject wasn’t talked about and she didn’t think parents would have had any idea about it. In the school one therapist insisted that thinking about rights wasn’t something people generally engaged in:

***DT1** (School) ‘Actually, nobody thinks about his or her rights, whether it’s in the town or in the village. It’s more or less the same everywhere. It doesn’t matter if they’re educated or not... There have been lots of campaigns going on these days and I think people are becoming more aware on these issues, but it will take time’.*

Integrated education was mentioned by one of the development therapists in the school in relation to the admission of a child who had learnt to walk. A bribe had been given to secure admission but from the second day of attendance other parents had complained and the child was withdrawn. The therapists didn't consider they had a role to play in this area. Their perceived role was strictly confined to child development and parental support. Their ideas appeared to be strongly linked to emphases imbibed through training.

6.1.5 Strengths and Weaknesses: Developmental Therapists

Both units showed commitment and empathy towards families. The five developmental therapists had been exposed to different approaches towards their work and reflected the training emphasis. As a female group they were comfortable in their interactions with children and mothers. Mothers were clearly able to benefit from this arrangement. The comparative lack of attention given to fathers' needs was a potential factor in decreasing their effectiveness, particularly as the fathers attending clearly wanted to do the best for their child and would have engaged with a male counterpart who was knowledgeable, if this had been arranged. The unit was located in the National Children's Hospital in the capital city and there was therefore little opportunity to engage with other members of the family apart from the accompanying adult. One developmental therapist suggested that greater attention to wider family power structures, particularly in rural communities, would prove helpful in developing better strategies of management for families with disabled children.

The main activity observed practically in both units was physiotherapy, despite claims that they were giving a total package of care. Although the syllabus for the proposed training wasn't available, the use of visiting foreigners from London suggested that the focus in training would be the standardisation and development of existing skills.

Personal experience enabled individual developmental therapists to relate to the social positioning of the mothers and to hierarchical, patriarchal family structures. Personal knowledge and experience of community life was being utilised by individual therapists, for example contacts with traditional healers were sensitively condoned though not encouraged. However despite this, there was limited acknowledgement that indigenous knowledge could be more explicitly used to inform and broaden

approaches to intervention. Twible and Henley (2001, p.158) commented that education about culture and community needs to be embedded across all curricula and permeate all aspects of the education process. This knowledge was readily available and accessible but its value appeared to have been overlooked in favour of an emphasis on attention to medical factors.

In the school situation, developmental therapists were more focussed on teaching parents handling skills and educating them about managing the child's condition. The use of the distance training package for families living outside of Dhaka was also in evidence. Limitation in school places and long journeys for parents meant not all children seen for therapy attended the school. Parents were also required to contribute a fee towards their child's attendance in the school. The level required depended on the father's income.

The practitioner model being demonstrated by developmental therapists in Bangladesh was closest to a wellness model according to categorisations offered by Trede and Higgs (2008) and based largely on an individual model of disability. The role of the recipient was largely passive with the therapist acting largely as the expert (Cunningham and Davis 1985). In the school setting elements of a 'transplant model' (Mitler and McConarchie 1986) were also evident in the therapist-mother relationship. This model emphasises parental teaching where technical knowledge is 'transplanted' into parents.

An understanding of a rights-based approach to disability was poorly appreciated by developmental therapists. Their perception was that any attention drawn to rights had had little impact to date on the lived experiences of families with disabled children and the role they had, did not include informing families of their rights or advocating for change. The report by Rahman (2006) which identified the failure of the government to implement the National Plan of Action emanating from the Bangladesh Persons with Disability Welfare Act of 2001 (as discussed in chapter one) suggested there was some truth in this opinion. The absence of a focus on rights related also to its lack of emphasis in training and also in the organisation's focus. Despite the fact that the unit and the school were also clearly hampered by lack of funds, there was no evidence of any involvement with groups such as NFOWD campaigning to promote structural changes. Strong links with overseas donors who were empathetic to the work being

done were the preferred mode of raising funds, in addition to the fees raised from parents.

Gender influences appeared to be highly significant when exploring aspirations held by this small group of developmental therapists. As a female group, developmental therapists were noticeably less ambitious in outlook compared to the group of Leprosy Physiotherapy Technicians who were predominantly male. Four out of five were largely ambivalent toward achieving an “accredited” qualification having already worked for several years in this role without such a qualification. The desire to gain a certificate in developmental therapy was largely in order to validate the role they had. The appearance of BSc students brought their lack of certification into focus, despite their considerable experience, because of status implications. The intended introduction of an accredited diploma level qualification in developmental therapy was an innovative initiative, the results of which remain to be seen.

6.2 Section Two

6.2.1 Leprosy Physiotherapy Technician Training

The main body of physiotherapy technician training was the recognition and management of physical aspects of the disease process. Teaching followed an established nine month curriculum developed by Leprosy Mission International. The ratios of males to females were higher in Bangladesh in both detection teams (Leprosy Control Assistants) and groups trained as leprosy physiotherapy technicians. The five leprosy physiotherapy technicians (Lep Tech) interviewed consisted of four males and one female. The female technician interviewed was the only female employed in this role, in this project. Richardus et al (2009) noted that new case detection rates for females between the ages of fifteen and thirty were low by comparison with the male rates at the same time. They linked this to socio-cultural characteristics of the Bangladeshi society, gender differences in exposure, health seeking behaviour and opportunities for case detection. The consequences of detection in this age group of females may have been an important factor influencing health seeking behaviour. The higher ratios of male: female in both the detection teams and technicians suggests that gender sensitivities were not being equally addressed.

The course also did not have recognition from the Bangladesh government even though its technical quality was high. All technicians had attended several shorter day courses arranged to supplement their effectiveness and three of this group had recently completed a further three months course. This had equipped them to treat other common impairments in line with policy changes in the project. The director in the participating project informed me that the project was moving towards the inclusion of treatment for other conditions.

In contrast to developmental therapists this was a homogeneous group in terms of training and they had all achieved the same qualification as a leprosy physiotherapy technician (Lep Tech). Three of the technicians were already treating other common conditions, in keeping with a policy decision to move away from a single focus on leprosy, towards its integration with the treatment of other conditions. One of the prime reasons stated for this integration by health planners was to reduce stigma attached to this disease (Arole et al 2002).

One of the technicians was interviewed at a Gaibanda-Joypurhat field clinic (Appendix 7) and the remaining four, including one female were interviewed by arrangement in the physiotherapy department of the hospital linked to the training centre. All technicians interviewed worked in a mixture of small rural clinics with a small number of home visits and also in hospital based work.

6.2.2 Practical Role with Users

All five technicians were able to describe their clinical role with relative ease and each described a detailed series of practical activities and health education which varied only slightly in accordance with the setting. This homogeneity reflected their standardised skills training. All descriptions followed a similar pattern described by one technician as follows:

Lep Tech 3 *The day I stay in the hospital, I actually provide exercise to the patients, assess new patients, provide new plasters and remove old plasters, ulcer management and health education.*

..I try to find out if the patient knows anything (about leprosy).When they miss one side, I note it and when they've finished I let them know what they've missed out...

Then we go to leprosy clinics. We assess there and try to find out what the patients need and try giving management based on that. We admit them in the hospital if they need hospital admission...

We also do other work in the (field) clinic...ulcer care...we do it ourselves...we provide dressings... We have some other work on the field...we do follow up and P.O.D. (Prevention of Disability)...The patients who need this but don't come to the clinic...we go to their houses and give them follow up. We give them both pre and post operative follow ups'.

A similar service was provided to government hospitals in his work region once a month by one of the technicians. Technicians were trained to recognise which of the users needed steroids and senior staff could then provide these. The confident descriptions by all technicians interviewed indicated the high levels of technical training they had all received. However their background experience and knowledge of the community had also equipped them with an understanding of the social aspects of disability. All Leprosy Physiotherapy Technicians were drawn from the districts in which they worked, a largely rural area punctuated by small towns in northern Bangladesh. Three of the group had also achieved previous degree qualifications, two at Master's level and one with a degree in sociology.

LepTech2 (Female) *'Personally I'm little bit emotional about the helpless because my background is that; I'm from a very poor family and I've struggled a lot to grow up. That's why I particularly feel for poor people....I thought I needed a job that would allow me to serve for people anyhow'.*

Finding employment had been a main factor in their decisions to apply to become Leprosy Physiotherapy Technicians, combined with humanitarian concerns. Another technician described his decision in the following way when faced with two opportunities:

LepTech4 *'I got the option for training like this...I thought "this one will allow me to deliver service and I'll feel satisfied that I'm able to do something for the helpless. On the other hand I'd get some money from the (other) job"... finally I chose to come this side'.*

6.2.3 Social Perspectives

All technicians identified poverty, unhesitatingly, as the greatest problem for people affected by leprosy and for all disabled people. They considered this to be the determining factor in reactions to it. For example:

LepTech4 (Male) *'Their biggest problem is poverty, secondly their health. It's not a problem if a person's hands or legs have been impaired and he owns a two*

storey building. People will go to his house and sit and talk but a beggar who doesn't have room in his house where people can sit down, everyone hates the sight of him. This is a social disease'.

LepTech3 (Male) *'Their economical problem is the biggest problem. They spend almost everything and even sell their property for the treatment... there's hardly anything left'.*

As in other parts of Bangladesh, honour was an extremely important consideration, discussed previously by Pryce-Jones (1989) (Section 2.5.1). Technicians linked the loss of status for males as the provider in the family with the loss of ability to generate income and command respect, thus loss of income also had a psychological impact for males.

LepTech4 (Male) *'There are both physical problems and social problems. His family won't show him the respect he used to receive before as he can't earn anymore and he has to depend on others for everything...I don't know the solution'.*

It was noticeable that all the male technicians chose to describe male concerns when asked about the impact of the disease on a person's life. This may have reflected the fact that they routinely saw more males than females, or that they considered the economic impact on families to be paramount and this depended mainly on males. This may have also related to hierarchical considerations in a strongly patriarchal context.

The female technician mentioned not only the gender problems faced by female service users but also her own difficulties as a female when faced with the task of treating male service users:

LepTech2 (Female) *'Sometimes female patients can't be free (open) to a male and they can't share the personal problems they have. That becomes the easiest with female technician. From this perspective, I think it's a very good advantage (to be female) and disadvantage?...sometimes I can't provide proper service to a male patient. That's a disadvantage for me'.*

Hirsi Ali (2007) noted the socialisation in Muslim families towards obeying and respecting men (Chapter two, section 2.5.1) and cultural pressures restricting physical contact between men and women who are not related. Acting on male advice, the female technician interviewed had devised a strategy to dismiss questions around her motives and keep interaction at a professional level when treating male patients. This

included providing an option for males to be treated by the same gender. Thus the gender issues were being surmounted to some extent by individuals as they arose.

LepTech2 (Female) *'...Sometimes a male patient may think, "What can I learn from a woman?" ...These kinds of issues have come. In that case, sometimes I say, "It's not important now to know if I'm a male or female. The biggest truth is that you're my patient now and I'm your service provider, I'm not thinking about that feeling now...So, if you don't mind, I can give you treatment and if you don't want (my treatment)... I'm arranging an alternative for you". That's how I manage'.*

She felt that gaining a qualification had given greater autonomy as a female to assert herself. Her views illustrated transitions occurring in the rural society in Bangladesh, previously described by Nahar (2006) (This was discussed in Chapter two, Section 2.5.1). She also mentioned that male staff were hesitant to treat females and were faced with cultural barriers that they needed to overcome. This resonated with my own experience in Bangladesh of being regularly requested by male therapists to treat any females who arrived, hoping to be seen.

6.2.4 Government Responsibility and NGOs

Beresford (1996) argued that having impairment does not always, and need never, result in greater poverty than that experienced by people who do not have impairments. Although there was limited scope within the organisation to help with economic rehabilitation of users through supply of loans and some retraining, this was necessarily very selective and all the male technicians felt the level of need far outweighed the scope of the organisation to meet it. They were critical of the government's lack of action to provide economical rehabilitation and felt that government should do much more to help.

LepTech4 (Male) *'The government can help a lot more than us in this matter. They've got the scope to make a budget for them, but we (the organisation) don't have that scope or financial ability. So the government should take action and come forward for helpless and disabled people... (that way) they'll find a way to get on with their life....'*

LepTech1 (Male) *'They speak about their family problems sometimes but...In these situations; actually we don't have anything to do (can't do anything about it). The rehabilitation (job re-training) provided from here is given to very few patients, it's not done broadly. That's why we can't do much'.*

Despite their keen appreciation of the inertia of the government to take actions towards addressing the need for economic security in persons affected by leprosy, perceptions of their own role did not include any action linked to raising awareness of

rights, support for self advocacy or collective lobby of the government. Despite their proven high ability levels medically the group expressed a ‘we can’t do much’ stance politically. They were all aware of acute material needs of users and yet maintained a strongly individual/medical approach to disability. Viewing disability as a social phenomenon calls for a response at a social level. At a personal level the group appeared to be well aware of the need for socio-political changes, and yet felt it was not their role to facilitate these in any way. This produced an element of frustration in the face of glaring needs they were aware of. In comparison to the male technicians, the female technician was more accepting of the status quo. She was also less analytical and less critical of government action.

Efforts by the State to provide basic necessities are included under the National Constitution of Bangladesh (1972) and are included in the basic rights of all Bangladeshi citizens (as noted in section 2.1.2). One of the male technicians drew attention to the need for disabled people to be able to access education to equip them more adequately for the job market:

***LepTech4 (Male)** ‘...Whereas we haven’t ensured education for disabled people or our government hasn’t been able to do it, isn’t it unrealistic to think about jobs before education? Without ensuring education they can’t propose employment’.*

Priestley (2003, p.202) noted that access to employment in the majority world is a matter of economic survival and yet, in many countries, disabled persons’ needs for economic participation are barely recognised. Dube and Charowa (2005) also argued that poverty is a symptom of structural imbalances and results from a lack of access to resources needed to ensure sustainable livelihoods. As a non-government organisation, the Leprosy Mission International works in partnership with national governments and other NGOs and therefore channels of communications are already in place for their projects in Bangladesh. Given the ratification of the UN Convention on the Rights of Persons with Disability in 2008 these channels could be utilised further to actualise structural changes towards more equitable access to resources.

6.2.5 Changing Public Perceptions

All technicians included ‘prevention of deformity’ activities as a part of their practical role. Stigma in leprosy is sometimes considered to be synonymous with visible

deformity (Kar and Job 2005). Although the technicians linked stigma to the presence of visible deformity they were also aware that this was reducing:

LepTech5 (Male) *'Yes, stigma is lot less than before now, but, it still exists to some extent in some areas...not much'.*

They reported that for men, visible deformity affected their chance of employment. When asked what would happen if a man had lost a number of fingers as a result of the disease and tried to get a job, the following response was typical:

LepTech3 (Male) *'In Bangladesh, they'll not want to give you a job easily. They'll think that it's a leprosy patient. But, there are many places where people don't understand and possibly they'll think it's from an accident. If people say to you, "You don't have fingers?" you can say, "I had an accident". Maybe you'll have to do some talking when they ask you how it happened but, if you say that you have leprosy they won't give you a job'.*

For females affected by leprosy a distinction was made between those with visible deformity and those with skin lesions when the impact on marriage chances was discussed, relating this also to levels of public awareness.

LepTech3 (Male) *'in those areas where it's been publicized a lot.....marriage is not a problem at all. Suppose she had a spot and it was cured by treatment...people wouldn't worry about that, but they won't marry someone who has a deformity... I don't see that attitude'.*

In their experience the public's fear of entering the leprosy hospital or visiting the roadside cafes located outside the main gate had lessened. They considered that two things had contributed to this 'social development', namely the effects of community health education around leprosy and the policy decision taken by The Leprosy Mission International to integrate the treatment of users affected by leprosy with other types of impairment:

LepTech5 (Male) *'We've been watching something...people used to get scared to hear about leprosy before...now after doing some work with general disability, big (rich) families now know that we're working together with them....They're bringing their children...they're standing beside the leprosy patients. They're not scared anymore. From that aspect...socially it's been improving'.*

LepTech3 (Male) *'Earlier if anyone just got inside Nilphamari hospital (DBLM), they would be known as a leprosy patient. Everyone would be scared to come inside and would not come inside. During my training, many people would not go to the restaurants (opposite the hospital) to have breakfast. Now people from outside are coming in and going out (of the hospital). The situation is much better than before now. Now it's much more developed than before, socially'.*

Although home visits were a regular part of their job role they also recognised that home visits were also problematic as it associated the occupant with this disease.

LepTech1 (Male) *'...if we went to their house they were scared that other people would get to know about them and would avoid them. Even now, stigma still exists in the community...'*

The similarities between users' reports presented in the previous chapter and leprosy technicians' reports indicated that technicians were very aware of the realities in the lived experiences of people with leprosy. The technicians were also aware of the impact of discrimination and described changes in their own attitudes. One technician described how his awareness of social exclusion and discrimination had developed. He had worked as a leprosy control assistant prior to his training as a technician, and had spent more time than the others on home visits. This exposure to the experiences of people with leprosy brought about the change:

LepTech5 (Male) *'...Ultimately, there comes a change in your attitude and I got it. You don't get it through training...it comes ultimately from your work- I'm talking about society...community...I had to spend hours and hours in the person's house, one where nobody would even peep in or look in...'*

'...I spent my time there to let him know about health education...self care. He'd sometimes take me to the tea stall.....Other people would be watching us there thinking things like "None of us mix with him. Why does he mix with him?"...and I benefited in realizing that they needed this... I felt that only when I went to a leprosy patient's house and exchanged ideas on the different problems'.

Another technician gave the following account of deliberate actions taken to reduce stigma leading to social exclusion:

LepTech3 (Male) *'In Rangpur...there's a shopkeeper...leprosy patient...no one would go to his shop or buy from him... We went there and bought betel leaf from him which he prepared and we ate... People kept watching us. As they were watching, they started talking about us...'*

'...We were normal people and we're going to his shop and having betel leaf from him and we're enjoying it! They became interested. They also saw that we were going only to that man's shop and not to others. So, they changed their attitude and mixed with the shop keeper'.

6.2.6 Aspirations of Leprosy Technicians

The educational requirement for the leprosy physiotherapy technician course was secondary school certificate (SSC) or intermediate certificate (HSC). The participants interviewed were mostly overqualified for the course. All had HSC or degree level qualifications or higher and one had a BSc degree in sociology. A marked

dissatisfaction was expressed, particularly by the male technicians, with the limitation in career prospects they had experienced once qualified. They were frustrated that there was little scope to develop and advance in a career. The most senior technician felt that, as the eldest son in his family, his failure to progress through a career ladder was 'shameful' for him. The specialised nature of their work also meant that they could not use their skills outside their employment to augment their income through private work.

A further source of frustration related to the lack of respect shown to them by doctors. Obligations to defer to instructions from general doctors were irksome, particularly as they often knew little about leprosy in comparison to their own knowledge. Doctors also did not appreciate the role of a leprosy technician. Their lack of status was compounded by the lack of government certification. The female technician appeared to overlook the authoritative stance of the doctors (who were male) and emphasised the surprise doctors expressed at her knowledge and ability.

LepTech4 (Male) *'Doctors think they are superior. They don't want to admit how important physiotherapy is. We can't even hope to get minimal importance from them as technicians'.*

Researcher *'But still, if you say that you've got a B.A. you're as intelligent as him aren't you?'*

LepTech4 (Male) *'They don't care about that! They never give it a thought'.*

Four out of the five technicians, including the female, wanted to improve their qualifications and felt that they had the capacity to do so. The female expressed the need for any further study to fit in with her family responsibilities. The males wanted to know much more about activities in Dhaka with qualified physiotherapists and wanted to develop links with them. The technicians had enjoyed the three month course they had recently completed in order to expand their skills but felt that they had the potential to do a longer course leading to a higher qualification as a physiotherapist. They felt that this would give them better prospects and better opportunities.

LepTech4 (Male) *'The other training I've got ...apart from leprosy...a few days ago.....that's okay for keeping the work going. But of course there is need for a long course which would allow us to know more widely...and if there's any facility to get that kind of training...(we'd like to get it). We can't leave our job.....so, if*

there's any arrangement for in- service training or private training, a part time course... (this would be better for us)'.

LepTech2 (Female) *'Now I'm at technician level, but I've got a wish that,... I'll communicate with CRP (Centre for the Rehabilitation of the Paralysed) to know if they have any arrangement for private training for those who are married and maintaining the family and also working....if they have any training programme for them. I actually want to be a good physiotherapist so that I can provide good service for the people of my area and my district. That's my wish'.*

6.2.7 Strengths and Weaknesses of Leprosy Physiotherapy Technicians

Several strengths were exhibited by this group. They were competent and confident in applying their applications of physiotherapy to a high standard in leprosy. They all expressed an interest and satisfaction in serving people. All had benefited from a structured and examined course which focused on skills around impairment. Their training and experiences had also given them a wider knowledge of the social aspects of disability and particularly of stigma experienced by people with this disease. They had less clear strategies to mediate attitudinal change but were clearly utilising opportunities as they presented, and felt this was an important aspect of their role.

Although training was underpinned largely by an individual model of disability they were aware of the socio-cultural domains of disability and identified poverty as the main barrier to inclusion. Stigma was associated with visible deformity and its effects were gendered in nature. They acknowledged that the NGO they worked for had insufficient capacity to address the scale of economic need in the population of people with leprosy and the male technicians felt strongly that the government had a responsibility to intervene much more for those who were unable to work. A particular weakness in their training related to the absence of strategies to empower users for socio-political action.

A further weakness related to the lack of a career structure for technicians themselves, given their high, proven levels of ability and the low status they felt, as their qualification was not recognised by the government. Although they gained some satisfaction from work, they also expressed dissatisfaction with their technical status and limited scope to advance in a career structure. These constraints were exacerbated by the social superiority doctors assumed in dealing with them. As a group, male technicians were highly ambitious to avail themselves of any opportunities to go further. The female also appeared to modify her ambitions as a practitioner, with

other cultural demands upon her as a married female. These observations indicated a gendered factor in their role.

Gender factors were also evident in interactions with users. The female participant had developed effective strategies to work with male users and acknowledged the advantage of her gender when working with females. She also appeared to cope better with medical domination than her counterparts. The numbers of female technicians was small compared to male. There was evidence to suggest that gender sensitivity in services may be an important factor in addressing socio-cultural aspects of health seeking behaviour shown by users.

6.2.8 Chapter Six Conclusion

The chapter has sought to examine perspectives around service users' needs and understand perceptions of role in meeting those needs in two types of practitioner. Both courses were relatively short and provided a way to increase numbers of practitioners quickly in situations of low resource. Both groups were trained to intervene in the lives of users with a single type of impairment. Based on a consideration of the congruency of their roles with users' own perceptions of need, ways in which the knowledge emerging from both groups might be used to inform preparatory courses could be identified. This included a consideration of the satisfaction of workers with their roles as stakeholders in service provision.

It was noted previously that the way in which disability is learnt about and understood, affects the way people respond to disabled people in the society (Priestley 2003). Training of both leprosy technicians and developmental therapists was underpinned by an individual model of disability. Their focus of activity was aimed at reducing levels of impairment and restoring physical function. Personal knowledge in both groups however indicated a tacit awareness of social factors impacting the lives of users, but no strategy had been included in the therapeutic endeavour to utilise this knowledge. Higgs and Titchen (1995) stressed that personal knowledge should not be underestimated. Adoption of an epistemology of knowledge in teaching (as discussed in chapter three, section 3.1.3) offers a solution to this predicament especially where international personnel have been used to introduce training.

Both groups of practitioners were attentive also to psychological needs of service users. Leprosy technicians showed evidence of attempts to strengthen the personal identity of people affected by leprosy and reduce discriminatory social behaviour. Attending to attitudinal barriers at collective levels through community health education was also acknowledged to be an effective strategy and one in which leprosy technicians participated. However developmental therapists working in urban institutes had little contact with wider family and community members. This limited their impact on community attitudes and restricted access to their services. Attention to the location of training, backgrounds and subsequent deployment of developmental therapists in the courses planned are important considerations if greater access to families is to be achieved and attitudinal barriers in the community addressed more effectively.

Behavioural norms meant that the effectiveness of female developmental therapists to address male users' needs was curtailed and vice versa. Reducing the high ratios of males compared to females in leprosy workers may result in a more gender-sensitive services and increase uptake of these services by females. Although alignment of both groups with needs expressed by users showed a degree of congruence when compared with the analysis presented in chapter five there was evidence to suggest that changes noted above were likely to improve effectiveness of these services. Given the high levels of personal knowledge of culture and community displayed by leprosy technicians in particular, a greater role in empowering users to access their rights would be a relatively easy step to develop further.

Introducing structural and cultural explanations of disability more explicitly in both courses would challenge therapists to develop their roles in ways which address social issues more strategically. Developmental therapy training in Bangladesh has to date given little attention to a rights-based approach to disability. Developing a greater awareness of how structural barriers can be addressed could be an important step in moving the role of therapists from a largely wellness practitioner model, to a more capacity/empowerment model. This could result in significant long term benefits to marginalised groups involved.

In developmental therapists there was evidence to suggest that implementing a more standardised training will be beneficial. A particular concern strongly articulated by

male leprosy technicians was the absence of career structure. This area would benefit from further consideration. Incremental awards which provide a route to a gradual attainment of higher qualifications could lead to greater work satisfaction for students embarking on these courses. (This was discussed in Chapter three, Section 3.3.5, in relation to approaches adopted by ICRC and HI). The achievement of government accreditation both these courses would do much to enhance the status of these workers particularly in light of the high value placed on certified qualifications.

The next chapter will consider workers trained as community based rehabilitation workers using differing approaches and contrasting models of disability.

Chapter Seven

7. COMMUNITY BASED REHABILITATION WORKERS

7.0 Introduction

This chapter presents the perspectives of two groups of Community Based Rehabilitation (CBR) workers regarding the needs of disabled people in Bangladesh and the roles they have in addressing these needs. In contrast to the 'single impairment' groups considered in the previous chapter, these workers have been equipped with generic skills in physiotherapy as a part of their training and both groups see users with a wide variety of impairments from all age groups in comparable situations in Bangladesh. The background to the introduction of CBR was presented in section 3.2.8. where it was noted that a plethora of organisational models of CBR emerged following its introduction, prompting a joint positional paper from ILO, UNESCO and WHO (1994) which included the following statement:

'CBR may provide the means for all disabled people in a community to be socially integrated, or may be more limited in its achievements. This depends on the commitment of the community, its resources and the support services that it receives from both government and non- government organisations.'

(ILO, UNESCO and WHO 1994)

The chapter presents findings from two different CBR organisational models based on different explanatory models of disability and approaches to intervention. Clear differences emerge in the perceptions of user needs and in the subsequent outworking of the roles adopted by workers which have implications for disabled people. These reflect the adequacy of training approaches they represent.

The chapter is divided into three sections. Section one describes the course philosophies and nature of the training of both groups of workers and identifies the data set. Section two presents findings from the Community Handicap and Disability Resource Persons (CHDRP). This includes the nature of their relationship with users, perspectives around the needs of users and the interventions, limitations and challenges in their activities. Section three presents findings from the Community Rehabilitation Technicians (CRT), their perceptions of user needs, relationships with

users, interventions and their group identity. Strengths and weaknesses are discussed with reference to relevant literature. A chapter conclusion is then drawn.

7.1 Section One

7.1.1 Implementing CBR using the CAHD Approach

The first group of workers, known as Community Handicap and Disability Resource Persons (CHDRPs) were trained by the Centre for Disability in Development (CDD) in Dhaka. These workers implemented part of a wider strategy at community level and their role included the provision of physiotherapy. Workers were selected and sent for training by NGOs involved in development projects after managers had attended a two-day workshop on disability and development. The funding for training and subsequent remuneration of CHDRPs came from the sending NGO as no financial support was forthcoming from government sources.

Their training organisation, CDD, was established in 1996 as a resource for the field of disability in Bangladesh and was linked to an International NGO. Disability was approached as a development and rights-based issue utilising a concept termed “Community Approaches to Handicap in Development” (CAHD). In this approach ‘Handicap’ is defined as “not recognising the existence of disabled people excluding them from society and not providing services to meet their needs”. CAHD was seen as a way of implementing CBR (Krefting 2001). It works with development organisations to expand their existing programme activities in order to ‘recognise the existence of disabled people and people with impairments, and promote their inclusion in society and the subsequent provision of services to meet their need’ (Khan 2003b). CAHD seeks to change the focus of an existing organisation’s work by introducing them to a social rather than an individual construction of disability and providing them with a strategy for change comprising four components.

Activities are then directed towards these four components simultaneously and are implemented at primary, secondary and tertiary sectors of society: The four components of the CAHD approach are :

1. Social Communication: providing knowledge to people and organisations about disability.

2. Inclusion and Rights: providing disabled persons equality of opportunity to access their rights as citizens and participate in the activities in their families and communities.
3. Rehabilitation: providing assistance to people who have impairments and to disabled persons that will minimise the functional difficulties that are the result of their impairment and maximise their personal development. This comprises basic rehabilitation services in the community and referral services to meet the special needs of disabled persons.
4. Management: ensuring the three activities are implemented simultaneously and are relevant, efficient and effective.

The strategy ultimately produces policy and legislation whose implementation makes inclusion apparent (Krefting 2001). However, this section of the research was primarily concerned with the implementation of this approach at primary level.

The five CHDRP community workers who participated were drawn from five different development organisations. The arrangements for these interviews were made by CDD staff and took place in one of the offices in CDD in the evening. The opportunity for these was occasioned by the attendance of around twenty-five CHDRPs on a short training course as part of their ongoing development.

All participants had previously completed their basic three month training as CHDRP workers and had received supervision initially in their fieldwork to develop their skills. Their practical work experience was therefore totally community based. The training institute consisted of a small number of classrooms and offices with on-site accommodation. All kinds of impairment were included in their training. The participants consisted of three male CHDRPS and two female CHDRPs. Their respective work locations are shown in Table 7.1 below.

Table 7.1: CHDRP interviews

Identification	Gender	Organisation/ Work location	District
CHDRP 1	Male	Gram Bikash Songstha	Bogra
CHDRP 2	Female	Poriborton	Sirajgonj
CHDRP 3	Female	Maizdi	Noakhali
CHDRP 4	Male	Kolpona, Anusobha, Obohoynagar	Jessore
CHDRP 5	Male	Syllhet Bodhir Academy	Sylhet

At the time of data collection, over 350 CHDRPs had been trained by CDD and were using a CAHD strategy. In terms of the estimated scale of needs this figure was comparatively small. However, the fact that their organisations were widely spread over five districts in different parts of Bangladesh meant that many communities at ‘grass roots’ level were beginning to receive these services for the first time. By June 2007 the number of CHDRPs trained from CDD had risen to 532 trained in 28 groups (Khan 2007) and has continued to grow steadily.

7.1.2 Community Rehabilitation Technicians

The second group of CBR mid level workers were known as Community Rehabilitation Technicians (CRTs), trained by an organisation initially founded in order to improve standards in healthcare, the Bangladesh Health Professions Institute (BHPI). This is the academic wing of the Centre for the Rehabilitation of the Paralysed (CRP), a large non-governmental organisation which has a number of services. These include specialist services for people with spinal cord injuries, a paediatric therapy unit offering a two week residential programme for children with cerebral palsy, a special education school, outreach clinics, and a CBR programme. All CRT workers were employed in the CBR programme of the parent institute. The CBR programme could be described as an Institute Extension Model (Thomas and Thomas 2003) discussed previously in chapter three (section 3.3.1). The two-year CRT training was underpinned by an individual model of disability and approached disability mainly as a health issue. The course was introduced in 1998 in order to train mid-level community workers to support the organisation’s CBR programme. All of the CRTs who were interviewed in this study were trained in the initial two years of the course.

The CRT group underwent a one-year theoretical training programme, followed by a 6 month institute based clinical placement in CRP and 6 months work in the community based clinics. The course was co-ordinated by a medical doctor. The goal of the course was to 'train multi-purpose technicians who can respond to the rehabilitation needs of disabled people in the community' (BHPI, CRT Course Document 2004). Teaching was by doctors, nurse educators, physiotherapists, occupational therapists, social workers, a counsellor, income generation staff and other visiting speakers. CRT training included little if any practical experience on managing visual and communication impairments as this was not a feature of the institute. Practical learning experiences of CRTs had taken place in its main institute where experience was gained in spinal cord injuries and other neurological and musculoskeletal conditions and it included the use of electrical equipment. Activities included awareness-raising, clinics, including mobile clinics, referral services, vocational training which was based in the main institute, and advocacy. There was no additional training given after qualification.

A new aspect of their CBR programme was the introduction of self-help groups in the geographical areas in which the programme ran. This was initiated by the director on his return from UK where he had completed his research on disability at the University of Leeds. The introduction of these groups represented an initial move to align the CBR programme with social model perspectives around disability. The aim of the self-help groups was to start to identify problems faced by disabled people and apply pressure to achieve their rights. Some of the CRT workers were involved in arranging these groups. The five CRTs interviewed were working in two of the districts. Four separate visits were made to work locations to conduct interviews with CRTs. On each occasion I noted observations from these visits in the field notes. The table below shows the location of the data collected for each CRT interviewed. Sections two and three of this chapter will present findings from each of these respective groups.

Table 7.2 : CRT interviews

CRT Identification	Gender	Interview/work location	District
CRT1	Female	Deldua	Tangail
CRT2	Male	Kaligong	Gazipur
CRT3	Male	Mirzapur	Tangail
CRT4	Female	Shokhipur	Tangail
CRT5	Male	Gazipur District Hospital	Gazipur

7.2 Section Two:

7.2.1 The Nature of the Relationship between CHDRPs and Users

CHDRPs were employed by organisations working in the area in a variety of development fields and engaged with rural communities mainly in home environments. They considered their ‘users’ to be families where at least one member had an impairment and the wider community of which that family was a part. The relationships they established with these families was informal and comparable to that of a support worker. They repeatedly mentioned that they stressed to families that they were not doctors. They indicated that in the village environments different terms were allocated to them including a term meaning ‘umbrella sister’. This referred to a television advertisement which had used a green umbrella as a logo denoting emergency care for rural areas.

CHDRP2 (Female): *‘Actually they call me by different names in different areas. Some say “Doctor-sister” is coming, even though I tell them I’m not a doctor. Some say “Sathi apa” (Umbrella sister) is coming’.*

The process of acceptance in a community was important and both females mentioned that this was easier if they were locals and if their family was known and respected in the community. They identified where disabled people were living by talking to people in the community.

CHDRP3 (Female): *‘There are little shops in the village, we stay there. When we take tea, people come to us and we get to know about disabled people through talking to these people’.*

There was an initial resistance and suspicion about their motives from the community. An assumption that there was a financial motive for their appearance was common.

This was linked with previous experiences of exploitation and a marked distrust was evident :

***CHDRP1 (Male):** ‘We face this type of problem many times. They think “They’ve come here to do business. They want to earn by using us and that’s why they’ve come to a new village for work”. We have to explain to them that we work for their development.....and that we don’t take money from them. We provide these services free’.*

They reported that in new communities in which they began working a pervasive atmosphere of distrust and suspicion was very evident. This was based on previous experiences of NGOs who had worked in the area who they said had exploited them to obtain funding for NGOs.

***CHDRP2 (Female):** ‘When we go to the village first, they think that a doctor has come and he will give medicine and they’ll get cured. Some others say, “They’re all frauds. We’ve seen many doctors like them”. They say, “Go away, get lost...you’ll list our names and get money from the foreigners using our names and pocket it yourselves”....Many organizations have worked in that area at different times, maybe not on disabled people but on other issues. It seems that the people were very angry with them (NGOs) and they still hold that distrust. We can’t blame them. They’re victims of the situation’.*

Over time the distrust gradually reduced as they worked with families and evidence of their intentions became clear. Sometimes their arrival was linked to the arrival of medically qualified personnel and communities expected to receive free medicines. (This was possibly linked to leprosy outreach projects who supplied medicines free of charge).

7.2.2 Prioritisation Around Community Attitudinal Change

All CHDRPs placed equal, if not more importance, on changing attitudes as on working with individuals and their families around impairment needs. They were aware that religious and other leaders in the local community strongly influenced local opinion. In their eyes negative attitudes were a major determinant in the lives of disabled people and if progress was to be made then these needed to be dealt with. Their views demonstrated an understanding of the way in which the personal was deeply embedded in the cultural (Priestley 2003, Thompson 2003), and a recognition that interventions were essential at both levels (This was discussed in Sections 1.5.1 and 2.1.1). For example :

CHDRP5 (Male): *'Counselling is so important for the family of the patients and for his neighbours.....more than for the patient himself. I mean it's more important for the community. Why I'm saying this? Because his psychology is influenced by his surrounding environment'....*

CHDRP1 (Male): *'When I try to explain to people about disability then, many times, leaders of the village or the Mullahs don't accept it. There are lots of misbeliefs at work in them. We have to remove these first through awareness raising, then we can provide our services straight away'.*

They saw their role as related to many social aspects of disability and as one which included rather than comprised attending to functional aspects of impairment. Their strategy was to make a broad-based assessment of the overall situation before prioritising and then working for change at several different levels. Negative attitudinal factors were seen as having a cumulative effect on individuals and required intervention at a collectivist level, appealing to cultural beliefs and values. (The importance of recognising this factor was discussed in chapter two, section 2.5.4).

CHDRP5 (Male): *'His mentality is not that bad initially but the negative attitude from his family creates an impact on his mind. He becomes frustrated thinking about the negative issues. Family sometimes makes comments like, "He's done so many evil things this is the punishment for his sin". When he hears such comments he becomes more frustrated. That's why we have to provide counselling to his family and community'.*

CHDRPs used an informal approach to this aspect of their work. Working in pairs they targeted communities in locations where people congregated, for example in tea-shops and bazaars. They also capitalized on the interest commonly displayed in new people in order to challenge local interpretations of, for example, mental illness:

CHDRP2 (Female): *'We get a big crowd around; they want to know about disability. They call them 'mad' in the village but we explain to them. We say "That's not right. They are one type of disabled person"'*

7.2.3 Perspectives on Needs of Users and Social Change

In contrast to all other provider groups, the subject of rights and the need for equality was voiced spontaneously by CHDRP workers as a pressing need of all disabled people. They stated that most of the people they saw were very poor and needed employment in order to generate income. Bringing this about called not only for a raised awareness of rights but also attitudinal change at several levels including governmental level.

Contributory factors in the failure to actualise rights in Bangladesh were discussed previously in Section 2.1.2 and identified both structural and cultural factors. CHDRPs

were aware that without change at personal, cultural and structural levels little was going to happen.

CHDRP5 (male): *'We have to make them aware of their rights...and opportunity for a job; qualified polio should get a job. If we think forget about his disability and think about his quality, then he's equal to us. But they won't give him that job..If this can be changed, and everyone is aware then..*

A change is required everywhere. I don't think it's appropriate only trying to change the mentality of the people in the village, I think government, not (only) government, everyone, everyone has to secure his rights, they have to change their attitude. Only then will their rights be preserved (fulfilled)."

The vocabulary used by CHDRPs e.g., 'a qualified polio' indicated that their training approach categorised disabled people according to impairment. This categorisation was used in their training as they accumulated knowledge of different conditions sequentially over a period of time. For CHDRPs this included all types of impairment and common conditions seen in both children and adults. However their answers to the questions probing their appreciation of the needs of disabled people indicated that impairment needs were not necessarily seen as the main need. Several other needs were mentioned. These related to poverty, exclusion, psychology, advocacy, appliances, employment, education and other areas. Decisions about what to address were based on several factors including resources available in the organisations for which they worked and the referral systems they could utilise. The wide variety in their answers indicated that they were essentially problem solving and then responding to each situation they encountered:

CHDRP1 (Male): *'For a child if physiotherapy is necessary we give that ...so far as we have learnt from this training. Someone else may not need physiotherapy but needs income generation, we arrange this or we provide him with some financial support from our organisation'.*

CHDRP5 (Male): *'We provide counselling for them, we refer them to other hospitals or doctors if they need other treatment. If they need financial support for buying assistive devices, we help'.*

CHDRP5 (Male): *'We provide physiotherapy as they need. We also provide hearing aids'.*

Poverty and income generation was addressed for adults to the extent to which they had access to resources. For children, school admission required advocacy. Equipment needs were addressed utilising locally available resources or using skills they had acquired. The Training Centre (CDD) had run a course in paper technology to teach

CHDRPs how to make simple items of furniture and toys from discarded paper. (This course had also been run in CRP but none of the CRTs had attended)

CHDRP5 (Male): *'Most of the patients are poor. We try to provide vocational training for them. If a boy is not going to school, we take him to the school. Maybe the seat in the classroom is not suitable for him - we arrange a special chair for him. We talk to the teachers about the child going to school'.*

CHDRP2 (Female): *'When we handle little children we provide exercise...Suppose I've got someone with fine motor problems, in that case we make toys which would encourage fine motor work. They call it a kind of device but it's a toy'.*

7.2.4 Limitations and Constraints Faced by CHDRPs

The CHDRPs also had developed referral networks over time which they regularly used but they were aware of the need for better referral channels. They did not have a large central organisation to which they could refer and so building multiple networks with other organisations was important. One of the five CHDRPs interviewed mentioned liaising with other organisations to enable people with severe facial disfigurement to access surgical camps. This highlighted the need for access to information about what was available to them. Several other difficulties were faced by engaging closely with families. All CHDRPs interviewed were aware of the activities of various healers. Because CHDRPs also engaged with the community in the home environment they found themselves in frequent contact with traditional healers in rural locations. The traditional healers were usually well known and almost all were males. They were regularly the first contact for a family with health care issues. All CHDRP participants were well aware of their activities saw themselves as needing to win ground from what they considered to be 'kobiraj territory'.

CHDRP4 (Male): *'We have to face many of them...We have a lot of bargaining with them, like a quarrel. They say that their work is more important (than ours), but we don't support kobiraji work'.*

All CHDRPs had encountered families who had been cheated by kobiraj or given empty promises for example:

CHDRP2 (Female): *'They call them "Boidday" in my area (i.e. someone who provides treatment in rural areas). They give tabiz (Spiritual amulets), take their money and go away cheating them. They say that it will get cured but we know actually, that it will not get cured. How can that get cured? A child who is nine years of age and can't change his position on bed - how can he cure him? It's not possible'.*

Their main strategy in dealing with the problems they encountered with kobiraj was to concentrate on gaining the family's confidence:

CHDRP3 (Female): *'They (users) say, "We've seen kobiraj; we've taken holy water". I say, "It's good that you've taken holy water but can I see your child? Let's see if that holy oil is beneficial or my physiotherapy is beneficial." That's how we manage.'*

CHDRP4 (Male): *'We try to win over patients to us who have been treated by kobiraj. Doing that proves to the family the difference between Kobiraji and us'.*

Four of the five CHDRPS related incidents occurring during overlap with a visiting kobiraj. Confrontations with kobiraj had a gendered element in the verbal exchanges. Unlike their male counterparts, female accounts of exchanges with kobiraj suggested that they were challenged more aggressively by male kobiraj encountering female competitors on his territory. However, confrontations reported by female CHDRP workers contained an element of triumph and resulted in greater confidence and self-efficacy in female workers. One of the female CHDRP's recounted how she dealt with a threat from a kobiraj:

CHDRP2 (Female): *'There was a big quarrel and there was a huge crowd of so many people in that area...Later he left.. He threatened me, "I'll harm you in such a way that you will have to search for me all your life to cure you."*

I said, "You do whatever you can but never come back to my child." They can't go to the children I see. I've seen these types of kobiraj, boidday!"

CHDRP3 (Female) *'I've even been in fights with them, for example I say, "This breathing on is of no use. It has never benefited me and will also not benefit my client now." If people say anything behind my back I don't care. I've got that courage!'*

Two male CHDRPs encountering similar situations appeared to handle these occasions quite differently and seemed to be only mildly perturbed by kobiraj. They didn't appear to be threatened by these encounters and did not report emotionally charged confrontations. One male CHDRP mentioned that he tried to educate one kobiraj in order to improve the techniques he was using rather than dismiss him outright. The gender differences apparent in the reports possibly reflected the higher levels of stress these encounters engendered for females who culturally felt pressurised to defer to males.

7.2.5 Accommodating Gender Norms in Community Work

Male CHDRPs reported needing to liaise frequently with female colleagues as it was often not acceptable for them to treat a female adult in the community. The gender norms were strictly adhered to and CHDRPs mentioned working in pairs in a location so that work could be divided according to gender. Women were always seen in their homes by other women.

The interviews with this group of CHDRPs were held in the early evening when the students were sitting outside the classrooms as a group. It was noticeable that the ratio of males to females in this group, who were all attending a follow up course, was more equal than in any of the other projects visited. This suggested that in their recruitment gender may have been a factor taken into consideration. It is significant to note that project managers responsible for recruitment of potential CHDRP workers were all required to attend a two-day disability awareness training course, prior to recruitment. This observation pointed to the impact this training may have had on managers' selection, although this was not investigated further.

Both female CHDRPs reported difficulties they had faced as females working in the community. The pressures for females sometimes came from other family members objecting to the work they were doing, as moving from house to house gave them a more visible profile in rural areas. This was much less of a problem when the therapist was working in her own home locality and was therefore known to the community. Their work also involved crossing the normal gender divide for example in entering teashops frequented mainly by men. Although this was tempered by working in mixed pairs (one male with one female), it still brought harsh criticism for females from their families. One reported that she had tried to solve this by seeking employment in a private clinic being run by a physiotherapist.

***CHDRP3 (Female):** 'I said to him, Brother, I'm having loads of problems from my family about this job, it's better I start working in a private chamber (clinic)'".*

It was apparent also that the female CHDRPs occasionally were at risk when working alone. One reported the following incident which she had successfully negotiated:

***CHDRP2 (Female):** 'Once I was going to the field and a mentally ill young man ran to me and grabbed me from behind. I was screaming. He was big and a handsome boy. I thought he was a sound person and was doing that to harass me. Many people gathered, hearing me scream. Later I got to know that he was*

mentally ill. I sat him by me and talked to him with care. Now I'm seeing him as a client'.

As a whole the group of CHDRPs felt that they were poorly remunerated for the job they did and that higher levels of payment should be given. Despite this, all appeared to be interested and deeply engaged in their work and challenged to develop at several levels.

7.2.6 Field Supervisor's Comments on Activities of CHDRP Workers

Field visits to the working environments of CHDRPs were not attempted as these would have involved extensive travel. However, contact was made with one of their field supervisors, a German physiotherapist who, after performing this role for two years, had returned to Germany. He provided written comments on their role, which were very complimentary and included the following:

'... another plus point is normally they not only check them in a medical way, they also have picked up some knowledge about the ADLs, (Activities of daily living), what suits them best to overcome their handicap, including house (WC, kitchen...) and also how can they get to school, not always a wheelchair is appropriate. Anyway, so these things they should be able to manage and what I have seen they are very strong at that.

'They also find out local woodworkers or similar staff to manufacture in the village. They got training on assistive devices, and there is also another 1 month's course, as far as I remember, where they can intensify their knowledge. They also get training in advocating so they should be able to talk with the schoolmaster or village leaders and mothers to advocate for their rights especially for children and women. They are not only trained in physical disability they are also trained in blind and deafness and all kinds of mental disability.

'Normally they are well accepted by the poor and the client's family. There is still superstition around and firstly they don't trust, but, after seeing some success, they are happy and grateful and of course, in this sense, it will spread.

'... as a physio or an OT or a speech therapist you will always find something that could be improved, but that is the dilemma of the time they have, 3 months is a compromise. You could do much more but who is going to pay for 6 months or 1 year? And what they learn in their 3 months is really a lot... the knowledge on each aspect is very limited, so they have overall a good view, but they lack more specific knowledge.' (Stief 2007)

His comments highlighted several positive features about this group including a focus on rights with attention to advocacy and removal of barriers to inclusion. Physiotherapy interventions were largely concerned with improving function and use was made of local resources to obtain aids and appliances. He recognised that depth of

knowledge of subject areas was limited by funding constraints. This reflected the limitations on funding available to NGOs and an absence of government support.

Two features in his report reflected his own paradigm as a health professional from Germany. These were a strongly individualist approach and corresponding absence of comment on the importance of community attitudinal change. There was also no mention of conflicts with traditional healers, suggesting that these may have been less likely to occur if male foreigners were present and were, in effect, culturally contained.

7.3 Section Three

7.3.1 The Nature of the Relationship between CRTs and Users

The Community Rehabilitation Technicians (CRT) worked with comparable populations in the community. Although their work included a small number of home visits they functioned largely in small sub-centres. The place of home visiting was variable and did not feature regularly in the work load of all CRTs. The most senior CRT did more home visits than the others. One female stated that she only did home visits when unavoidable:

***CRT1 (Female):** 'I don't usually go to houses but sometimes there are cases when it's impossible to bring the patient here, in that case I have to go'.*

Another of the male CRTs saw these only as follow up visits for spinal injured patients after discharge from the parent organisation:

***CRT5 (Male):** 'They still haven't given a list of ex-patients of CRP. In the last meeting they said we would do home visits. Maybe we'll start from this month'.*

One of the male CRTs also worked in a small government hospital one day each week in a room regularly used for taking blood samples. Another worked in a space allocated to him in the union library. One female also mentioned going into the district hospital.

Whilst visiting the sub-centres to conduct interviews we were able to observe a number of interactions of users with CRTs. It was noticeable that users referred to CRTs as 'dactar' and were very respectful. One CRT commented that he was 'very proud and happy' to receive the honour this status afforded him. Two CRTs mentioned that they worked in private clinics in the afternoons once they had completed their main duties as CRTs. The main role identified by all workers was the provision of physiotherapy treatment to patients in the sub-centres:

CRT1 (Female): *'When people say "What do you do?" we say "We're physiotherapists." We tell them that we work with these kinds of patients and if they know anyone having these types of problem, we tell them to bring them to the sub-centres and we'll provide treatment and they'll get better'.*

CRT4 (Female): *'Our first duty is to treat patients, to identify patients, treating patients, going to the hospitals two days a week, treating patients in the sub-centres once a week'.*

CRT3 (Male): *'The work I'm responsible for...I have to provide physiotherapy services to the patients given to me by the committee. Therapy services meaning physiotherapy, occupational therapy...just rehabilitation therapy'.*

Given the strong emphasis on treatment, the main needs of users was probed further. Responses indicated that there was some recognition of the wider needs but these were seen as a secondary concern.

CRT5 (Male): *'They have social needs but I think treatment is the first priority for them'.*

The view of this CRT also suggested that although he recognised discriminatory attitudes he did not perceive his role as changing the attitudes of the local community:

CRT5 (Male): *'When he's little bit better, then he needs to be in the society. He's neglected by the society in different ways. Society calls him 'langra' (a lamb) they think it's not possible for him to do anything. His family has to understand that he's got these problems but he'll be improved a lot if he receives treatment in this way or he is taken care of in that way'.*

CRTs considered that the main benefit of their work was the provision of 'modern' forms of treatment:

CRT4 (Female): *'They now know that there's an alternative treatment available in the country. Physiotherapy and Occupational Therapy are very modern forms of treatment imported to Bangladesh from Europe. Now community people have got this information that there's an alternative treatment available in the country and we're providing that treatment. This treatment can cure the conditions that are not cured by medicine. Now people understand it'.*

Despite these claims there was clearly some confusion in CRTs regarding the efficacy of the treatments they gave and the potential these held in providing a cure. Observations suggested a lack of understanding about conditions that were not curable.

The CRTs were asked what they did if people with visual or hearing impairments attended the centres. The most senior of the five CRTS said that he directed people with visual and hearing impairments to organisations elsewhere. The female CRTs

mentioned that dealing with people with visual or hearing impairments was not regarded as part of their role they were at a loss to know what to do with them.

***CRT1 (Female):** 'Other people also come when they hear that we provide treatment for disabled people. Visually impaired people, deaf, and people with speech difficulty also come but we can't tell them anything. What will we tell them? We can't provide treatment for them. We just tell them something informal, that's all'.*

None of the CRTs spoke about working with adults with cognitive impairments, nor did they see any need to learn more about this group.

A charge was made for treatment in the sub-centres. CRTs were aware that for persons with a significant impairment, costs of private transport were high as travel on local buses was difficult and that this restricted attendance for persons unable to afford costs of travel and treatment. Although awareness of these different barriers was present in CRTs there was no indication that this had any impact on their role.

Throughout the sub-centre visits there was a strong male presence in both staff and attendees. As two group meetings were occurring in the sub-centres on the days we visited in order to conduct the interviews, we were invited to observe these. One of these meetings was a self-help group meeting and over twenty disabled people were in attendance. The main content of the meeting was a lecture on the rights of disabled people and all attendees sat in total silence during the entire length of the presentation and no discussion followed. I was very aware that I was the only female in the room. The coordinator informed me that this was the first time he had presented this talk. The content reflected changes being introduced by CRP's director after the completion of his studies on disability in the UK. Instructions to sub-centre coordinators to teach members of the self-help groups and staff about the rights of disabled people were clearly being followed albeit to an all male audience.

Observations recorded in the field notes detailed the lack of equipment in all three sub-centres visited. In one treatment centre this consisted of a wooden chair, a large double bed, a ball and a large sandbag. None of the centres visited had a designated area for children and there were no toys. The CRTs were asked about equipment needs. Electrical equipment was considered to be the main equipment need. The male CRTs saw this as a valid treatment option that would enable them to improve their treatments. None of the CRTs had attended the course offered in the parent institute

on paper technology. Only one user seen waiting for treatment had a walking-stick and this was clearly fashioned from the branch of a tree.

CRTs described their role as including activities around awareness raising. They were asked to describe these and reported that meetings were held in schools, madrasas and colleges. The content of the meetings consisted mainly of challenging misbeliefs around the causes of impairment and providing information about the availability of treatment from the sub-centres.

***CRT4 (Female):** ‘Usually we campaign on stroke, CP (cerebral palsy) and spinal cord injury. We tell people how they happen. We tell them how spinal cord injury happens....We tell them that usually it happens from falling from a tree, diving into water, we tell them the reasons. Then we tell them about stroke. We say “You call it touch of evil wind and take treatment from traditional healers or spiritual healers, it’s not right. Go to a doctor (Physiotherapist) and see what kind of treatment they provide.” We do whatever is necessary, we provide treatment’.*

7.3.2 Role in Advocacy and Financial Assistance

Where the CRTs acted on needs for income generation or vocational training they all did so by arranging the user to be admitted to the parent organisation in order to learn one of a defined list of skills that were available there. A limited number of loans was also available through this organisation though the mechanism for obtaining these was the responsibility of the most senior CRT.

CRTs were asked whether they had a role in advocacy. The male CRTs mention success in procuring funds from local beneficiaries or the local chairman for disabled adults by appealing and helping them with necessary applications:

***CRT2 (Male):** ‘Yes, there are many proofs of that. We communicate for him. We go to the bank or social welfare office with an application or necessary papers and we take the person with us...we arrange necessary certificate from the Chairman or granter (referee). We arrange them. We submit the papers and monitor it. We’ve achieved lots of response’.*

None mentioned arranging school admission for children. Treatment of children appeared to be a minimal part of the workload and this was largely left to the females who rarely left the sub-centres.

In response to questions around their own personal development male CRTs felt they needed to learn much more and were ambitious to do so and gain higher qualifications. They were especially critical of their training content which they felt had

lacked clinical supervision. They reported their frustration during their training around changes in the name allocated to their role and by discussions around whether they would be allowed to work independently or needed to be supervised by physiotherapists. No physiotherapists were employed in the sub-centres and this group operated independently, repeating treatments they had observed in the parent training institute. Both female CRTs were younger and had less experience than the males and did not specify any specific training needs.

7.3.3 Comparing Two Approaches to CBR

Both groups of CBR workers, CRT's and CHDRP's were working in comparable community settings where disabled people were likely to have many similar needs. The groups functioned very differently however and the approaches to their work could be related to the way in which they had been prepared for their role. Perceptions of the needs of disabled people and priorities in responding to those needs appeared to have been strongly influenced in both groups by the content of their training and role socialisation. A summary of the findings within both groups is presented in the table 7.3 below.

Table 7.3 : Contrasting approaches to community work in CRTs and CHDRPs

Feature of CBR approach practised	CRT	CHDRP – CAHD approach
Model of disability emphasised in training	Individual model of disability	Social perspectives of disability
Main focus for intervention	Individuals	Families and communities
Identity with users.	Doctor, expert.	Informal: auntie, uncle, sister, brother.
Main activity	Provide physiotherapy treatment in sub-centres	Address perceived barriers to inclusion especially attitudinal barriers in homes and communities
Self assessed areas for more training	Visual and communication impairments, assessment	More detailed knowledge of treatments.
Location of practical training	Healthcare institute	Community and homes
Service needs identified	More equipment needed.	Better referral pathways, more awareness of rights.
Costs to users	Clinic fee and transport costs.	Nil
Attention to and gender sensitivities in users	Low Male dominance in all clinics. Few home visits	High Staff ratios more evenly balanced. Female users seen in homes.
Model of practitioner	Illness and wellness	Capacity

CHDRPs were equipped to respond to a wide range of impairment needs including visual and hearing problems whereas this was a specific weakness in CRT training which reduced their effectiveness. Both groups were keen to learn, but CHDRPs had the advantage of a structured on-going learning programme. Learning needs, identified by male CRTs only, remained largely unaddressed.

The degree of congruency with needs of users presented in chapter five was low for CRTs and high for CHDRPs who seemed well informed and equipped at several levels to address discriminatory practices in the community. CHDRPs interpreted their role as being concerned with achieving social justice for a marginalised group and this included providing access to rehabilitation services. In contrast CRTs epitomised an 'institute extension model' described by Thomas and Thomas (2003), (noted in section 3.3.1). Their curriculum focused heavily on technical skills. Practical work experiences gained largely in institute settings were then transferred to community settings. This

failed to equip CRT workers with the ability to problem solve effectively at a wider level and appeared to curtail their effectiveness in community settings. Although CRTs were not unaware of the social circumstances of disabled people, they demonstrated a comparatively minimal role in engaging with barriers to inclusion.

The model of disability with which the CRT workers were aligned was an individual model of disability and rehabilitation and largely followed a traditional rehabilitation paradigm assuming a biomedical clinical orientation (Leavitt 1999). Criticisms of this approach were discussed in section 3.2.4. Within this paradigm, functional or psychological losses were assumed to arise from disability and are seen as the cause of the problems associated with it (Oliver 1983) and are therefore the focus of intervention. This approach failed to equip CRT workers with an understanding of the impact and significance of social factors in the lives of disabled people which were reported in chapter five.

The focus of activities in which CHDRP workers engaged emerged from an understanding of disability as a development and a rights issue, shifting the emphasis from impairment to addressing issues around inclusion (Baylies 2002). It was noticeable however that CHDRP workers often identified people with impairments in terms of the impairment, despite the fact that the CAHD strategy (Krefting 2001) approached disability from a social model perspective. Priestley (2003, p.192) drew attention to 'categorical definitions that tend to group people according to impairment labels of service bureaucracies' as being a factor influencing static identities ascribed to disabled people. Although this feature could be interpreted as being counter-productive to goals of CAHD (These are detailed in Appendix 3 and discussed in Section 3.3.1) and was less than ideal as a practice, the use of impairment labels, arguably, held some advantages in this context. Using medical descriptors offered an alternative to the use of derogatory Bangla terms for disabled people, previously identified in section 2.3.2, and aligned these workers with language usage in medical discourse in Bangladesh. Familiarity with these descriptors enabled CHDRPs to refer users to appropriate specialist services, an important aspect of their work.

The main emphasis in CAHD was on the recognition of the existence of people with impairments, promotion of their inclusion in society and the subsequent provision of services to meet their needs (Khan 2003b). The recognition of the outworking of

discrimination at three inter-related levels in society, personal, cultural and structural (Thompson 2003), and the need to address each of these levels, was an important aspect in the CAHD strategy. Unlike CRTs, CHDRPs saw their work as part of a wider strategy targeting societal change at these levels. This was a distinct strength of their approach.

There were a number of other strengths evident in the CAHD strategy. A major strength was the high number of development organisations in Bangladesh dispersed over a wide area who could potentially train existing staff to do this role. CRTs, on the other hand, were all employed in a single health project. This operated independently and lacked cohesion with the broader field of development activities.

The different relationships between workers and users in the two groups were important with respect to empowerment of disabled people, a major component of CBR (ILO, UNESCO, WHO 1994). Maas (1997) stressed the need to promote empowerment and encourage participation by disabled people. Power has been closely linked with having control and gaps in status between providers and users have been previously identified as important factors in considerations of power (Section 3.2.7). Attention to these power dynamics was more evident in the more informal relationship strategies promoted in CHDRP training approaches compared to superior status maintained by CRTs. The collectivist approach to families and communities also aligned CHDRPs with cultural norms in contrast to the more individualistic approach to CRT work.

Coleridge (1993) pointed out that political, social and economic forces all played a part in enabling people to gain meaningful control. The CAHD model employed demonstrated the use of a strategic approach to disability by approaching empowerment as a political as well as a personal issue (French and Swain 2008) and by supporting the uptake of rights. Attention to gender ratios evident in CHDRP training provided greater access to services for disabled women thus promoting more gender equity. The marked predominance of male CRT workers suggested that this feature was lacking in CRT training. These arrangements also meant that services for children were less likely to develop as this was seen as a female role. Additionally because home visits were not routinely provided by female CRTs this was likely to restrict access further to women.

A possible weakness for the CHDRP workforce was the visibility and vulnerability of their female workers. Because female CHDRPs engaged closely with the community and worked in home environments they also came into contact with traditional healers and confrontations highlighted the gendered power struggles occurring at this level. However, the challenging experiences reported by female participants also appeared to produce self assurance and increased confidence in their own abilities, an aspect of development not reported by female CRTs.

7.3.4 Chapter Seven Conclusion

Important conclusions can be drawn around approaches to training CBR workers that are beneficial in this context. The study findings presented in this chapter suggest that training approaches which adopt a culturally-attuned, development and rights-based approach to disability hold distinct advantages for disabled people. Training approaches which address disability as an individual health-related issue and offer institute based services along more traditional lines are more modest in their achievements, and in comparison do little to impact the marginalised position of disabled people within this context. The following chapter will examine the perspectives of professional physiotherapists in Bangladesh and the roles being developed by this group of healthcare professionals within this context.

Chapter Eight

8. THE PROFESSIONALS

8.0 Introduction

This chapter will identify the perceptions of the participants training as professional physiotherapists around the needs of service users and their role in intervention. It will also examine perceptions of their own development needs. This chapter will also examine processes of role socialisation occurring in these courses.

The chapter is divided into four sections followed by a conclusion. Section one describes the data set achieved with student physiotherapists. It also identifies specific features of the courses from course documents that are of relevance to professional education around disability. Section two reports perceptions of user needs held by Diploma and BSc Physiotherapy students. This is followed by an analysis of the way in which participants perceive their role with users. Section three examines role socialisation at an individual level i.e. anticipatory influences and experiences encountered during formal training. It examines participants' views of ways they think professional courses should be developed, their goals around preferred employment locations and notes further issues raised in relation to their role as healthcare professionals. Section four discusses changes that will align professional preparation more adequately with user needs. A chapter conclusion is then drawn.

8.1 Section One

8.1.1 Data Collection Planned and Achieved

The data analysis reported in this chapter is based on eight focus groups identified in the text and eight interviews with students on BSc and Diploma courses (Table 8.1). Graduate courses emphasised assessment skills, independent decision-making and individualised treatment planning. In one institute (CRP) the diploma and graduate students followed exactly the same course. The diploma students however took two sets of exams i.e. both BSc and government diploma exams. This unique arrangement allowed successful students to transfer into the BSc final year after completing their diploma. It was withdrawn in 2006. The government diploma students were trained in

the Institute of Health Technology (IHT). The entry requirements in this institute were lower than in CRP and the course was taught in Bangla. References to this group (Gov Dip IHT) identify students following the government diploma course only.

The Data Set contained a total of 8 Focus Groups (including a pilot focus group), and a total of 8 interviews (also including a pilot interview).

Table 8.1 : Data Set with physiotherapy students

Institute	Abbreviation in text	Year of students and type of data
National Institute of Traumatology and Orthopaedic Rehabilitation	NITOR	BSc (Ord) interviews (1 st year female and newly qualified female) 2 BSc (Ord) focus groups (1 st & 4 th)
Institute of Health Technology Mohakhali, Dhaka	(Gov Dip IHT)	1 st year Gov Diploma interview (male) 1 st year Gov Diploma focus group
Gono Bishwabidyalaya University	Gono	2 interviews (1 st year male & 4 th year male both BSc Hons) 2 focus (1 st & 4 th years BSc Hons)
Bangladesh Health Professions Institute (Centre for Rehabilitation of the Paralysed)	BHPI	Pilot interview (3 rd year male) BSc (Hons) pilot focus group 3 rd year (Mixed BSc Hons and Diploma together) 2 interviews (1 st year male and 4 th year female both BSc Hons) 2 focus group (1 st and 4 th year mixed diploma and BSc Hons)

Students are identified in this chapter according to course, institute and year of study and pseudonyms are used. Quotations reported from focus groups are identified specifically in the text. All other quotations are from individual interviews.

8.1.2 Variation in courses in participating institutes

Professional physiotherapy training is offered in Bangladesh via a BSc course lasting four years. An internship follows. This lasts one year in CRP and six months in NITOR. Government Diploma courses were three years in duration with no internship. Courses sometimes took much longer than these times to complete, particularly in the government institutes, because of strikes and delays referred to as 'session jams'. Course curricula from all participating institutes indicated that all courses were underpinned theoretically by an 'individual model' of disability. Two institutes (Gono and NITOR) used curricula which were very similar to that used in the 1970s when physiotherapy degree courses based on the British system were first introduced into

Bangladesh. Both curricula describe physiotherapy as: ‘...a branch of medical science which deals with the treatment of disease by physical means’ and state that ‘the physiotherapy programme is part of the medical services in hospitals, rehabilitation centres, geriatric institutions, home care programme which provide treatment and rehabilitation services’ (University of Dhaka Syllabus document for BSc(Ord) degree course in Physiotherapy, 1995 / Gono Bishwabidyalaya University BSc(Hons) degree in Physiotherapy Course documents).

The BSc course document in BHPI, an institute which has utilised mainly British volunteers more recently describes physiotherapy as:

‘...an evolving profession that emphasises the use of physical approaches in the promotion, maintenance, and restoration of an individual’s physical, psychological and social wellbeing, encompassing variations in health status.’
(BSc Physiotherapy Course document 1998)

This document also identifies ‘the need for physiotherapists to be able to respond to the changing context of healthcare delivery in the new millennium’.

The IHT Government diploma course describes a more technical goal aiming to :

‘...prepare Medical technologists (Physiotherapy)...to perform assigned responsibilities in physiotherapy departments of health institutes like hospitals, rehabilitation centres, health complexes and clinics to achieve the desired goal.’
(State Medical Faculty of Bangladesh, Curriculum for the Diploma in Medical Technology of Physiotherapy Course, 2001)

Course structure and content varied, but were all were largely based around application of differing physiotherapy treatment interventions for various injuries and medical conditions. On the government diploma course there were no physiotherapists on the regular teaching staff and the majority of teaching was given by doctors. The diploma training emphasised prescriptive application of techniques with a strong emphasis on electrotherapies. One course only (BHPI) included a theoretical module on CBR and a module on social welfare and inequality. All courses were offered in venues linked to hospitals and were largely focused on equipping physiotherapists for institutional based settings.

The amount of clinical experience given to the students on the courses varied according to the arrangements established with various hospitals. Clinical experience was provided in a variety of hospital locations on two courses (BHPI and NITOR). The

students on these courses were required to pay additional fees for these. In two institutes (Gono and IHT) clinical placements were limited to the hospital located on the same site as the training institute. In one institute (Gono) students were allowed only to observe a supervisor treating patients during their placements. The limited availability of physiotherapy services in all the major hospital placements meant it was necessary for supervisors from the training schools to accompany their respective groups in order to provide clinical supervision. The ratios of student to supervisor varied between placements. One teacher reported supervising 23 students on clinical placement (Swapan 2003). This group included students from two different year groups simultaneously. Dawson (2002) reported that debates by British educationalists have taken place regarding productivity when supervising groups of up to 3:1 student to supervisor ratios. A decision to allow a 4:1 ratio in Palestine was made in view of the shortage of supervisors there. Ratios in Bangladesh were clearly much higher and experience of the supervisor was sometimes minimal with some newly qualified students moving into teaching posts immediately. This situation highlighted the need for attention to standards in professional physiotherapy education.

At the time of data collection, only one participating institute (BHPI) offered students a placement experience in Community Based Rehabilitation. Students in this institute (BHPI) visited sub-centres where Community Rehabilitation technicians (CRTs) worked, and observed health education outreach activities. There were no established community role models for professional physiotherapists. BHPI had also initiated the development a placement known as Community Integration. This placement required students to make a small number of visits to the homes of spinal injured patients following discharge. (This aspect of the placement was later removed by national teaching staff). In the focus groups and interviews some of the more senior students who had made home visits were able to draw directly on their community experiences to illustrate their views.

8.2 Section Two

8.2.1 Perceptions of Physiotherapy Students Around User Needs

In all except one of the focus groups (Gov dip IHT), there were a mix of male and female participants. The overall male to female ratio of students participating was approximately 3:1. This ratio reflected the general ratio of professional physiotherapy

students training in all institutes. In two of the focus groups, certain females were extremely articulate. This contrasted strongly with the fairly reserved and submissive stance adopted by most other female students, particularly in mixed group settings.

In all the focus groups, the initial response to the question around the needs of users indicated that the majority placed treatment (impairment) needs at the top of the list. Usually one or two members of each group were less focused on treatments than the others, and more readily identified other issues. Various case scenarios were then described by the assistant researcher, and students' awareness of the social circumstances of the majority of users began to reveal itself. As the discussion progressed, responses indicated that it was common knowledge that most disabled people were poor. It was also common knowledge that disabled people were mostly seen as being useless and helpless by society. The following sequence of answers was a typical of responses to the question of what disabled people needed most.

Gov Dip IHT focus group

Delowar: *'They need good treatment.'*

Shuvo: *'They need physiotherapy.'*

Asa: *'After treatment they need money to run their family. If he's the only earning member in the family, his family gets into serious trouble. The whole family becomes disabled with him.'*

These social consequences were reported in a very matter-of-fact way and did not seem to perturb anyone particularly. It was a reality they were familiar with and 'the norm', for example:

First year BHPI focus group (male)

Assistant Researcher: *'Suppose there is a person who has lost one leg, living in the village...what will be in his mind and his family's mind? What will be more important to them?'*

Shanu: *'Earlier he used to earn and now he's been a burden for the family as he can't do anything alone. The society will see him as a burden. Sometimes, the neighbours say, "He used to work before but now he's a burden for his wife and children", some even say, "It's better if he dies".'*

Hasan : *'Yes!'*

The Government diploma students differed from the BSc students in that their course fee was much less costly. Several identified themselves as being from poorer families. Although none of them mentioned personal encounters, students in this group

displayed a much greater knowledge of interventions provided by kobiraj, sometimes describing them in detail and adding their opinions about their activities:

Rana: (1st year male Gov Dip IHT focus) *'There are two types of Kobiraj available in our country: one type of kobiraj makes medicine in traditional style using trees and leaves. The other type are those who provide sorcery and black arts for treatment. They use "Jadu-Tona" (magic-spells). People trust them blindly although they don't get any benefit from them.'*

The government (IHT) diploma students came from different parts of Bangladesh and their in-depth knowledge of kobiraji activity was indicative of their more rural backgrounds. In discussion around professional role, BSc students described a medical role and the government diploma group a more technical role. Students with experience of treating patients on placements related several instances treatment intervention. When they saw improvements in patients' conditions, they felt that this increased their self-respect and sense of pride in their role. They clearly felt that delivering treatment was valuable and very necessary for users and receiving honour and feeling honoured was of great importance to them.

Anil: (3rd year male BHPI in DMC ICU) *(Dhaka Medical College, Intensive Care Unit) '...a doctor himself came to us and said, "You've done a really good job here, could you teach something to our nurses?... Please give them some advice so that they can do well"... I think, yes, I really deserve this honour.'*

8.2.2 Preferred Role as Medical Professionals

Role perception was pursued with all the different groups in relation to how this might relate to community settings. The majority considered that here also their role should be confined to treatment and impairment needs. Certain of the male students voiced the opinion that social workers and others should be responsible for 'other roles'.

Sohrab: (1st year male BHPI) (Brother a doctor) *'It's also not true that it is the duty of a physiotherapist to go to the community and to serve there for people. This should not be the work of a physiotherapist because there are social workers and sociologists who are taught on this separate area. If I do their work, then why did I come into this profession?'*

The resistance shown by this student also extended to objecting strongly to the course inclusion of a module on welfare and social inequality:

Sohrab: (1st year male BHPI) *'I don't think this welfare and inequality class we have is helping us at all! Actually, it's disturbing for us!'*

These negative views towards community involvement were particularly noticeable in the wealthier BSc students. There was very little knowledge amongst any of the groups concerning community based rehabilitation. It was significant that only one institute (BHPI) had a clinical placement, which allowed them to go into the community as professionals.

One of the few female students who had been on a home visit, was enthusiastic about what she had managed to accomplish. Although accounts of community experiences were minimal, such positive expressions did suggest that more exposure to these scenarios might change the general negativity.

Humayra: (4th year female focus BHPI) *'I think physiotherapists have most important roles in the community. When I was there to visit a patient from CRP 6 months ago, his wife was just leaving him forever. Then we went there and did some counselling and the wife did not leave him. They're still together. My advice that day saved his family. It's an example how effective CBR can be.'*

One third year in BHPI had attended awareness raising sessions given in a school in the CBR project. He reported on the huge potential impact he saw to educate the public regarding basic health education. His reply indicated that he was well aware of the levels of ignorance that existed in rural communities around health issues, but what he was impressed by was the potential value he saw for effective teaching in healthcare.

Rofique: (3rd year male pilot focus) *'Because the health system in Bangladesh does not let people know about their problems it means if I've got simple diarrhoea, I'll go to an orthopaedic surgeon!...If the CBR programmes can be made colourful and attractive, then they can be effective for lots of people, we'll have to make it more colourful and attractive.'*

The role of health education he envisaged included aspects of prevention and warning of the dangers of unsafe practices, which were very common. The response of the group to his suggestions was, however, fairly flat.

When the possibility of facilitating others to address other needs was discussed, for example, advocacy for jobs, the consensus viewpoint was that they were actually medical personnel and their job was only to treat people in institutes or in 'private chambers'. The chance to develop more medical skills however and increase their scope of practice medically was seen as something they did want to attain.

Akheel: (1st year male BHPI focus) *'Our curriculum should be designed in a way so that we're not only limited in physical therapy....we should have the ability to*

cover everything at least with some skill in the community. If a patient who has come to me suddenly has heart failure or any other big problems like an asthma attack...we can't help the patient if we don't have a minimal idea on medicine. We should know some medicines to provide instant care. That's why our course curriculum must be upgraded- such as pharmacology, first aid. We don't have these in our country but our neighbour India has!'

Tahamina: (3rd year female BHPI focus) *'If we're working in the village, suppose, I don't want to work in the city and I've gone to the village. It's very common in the village that children will come with fractured hands and legs. If I don't know how to plaster, why are we there then?'*

A strong suggestion from the BSc focus groups, particularly the senior students, was that physiotherapists should be able to prescribe a number of drugs, order and interpret blood tests and should be equipped with sufficient knowledge to make medical diagnoses. Their answers indicated that they had very indistinct boundaries around the role of a physiotherapist, seeing this as a role that overlapped with traditional medical roles. Their views were influenced in part by their knowledge of older physiotherapists working in Bangladesh who routinely ordered tests and prescribed drugs and they felt that they should be equipped to do the same.

Obaidul: (4th year male Gono) *'If we say, "You do this test", we'll have to have an idea why he would do that test and what can be the result for that condition. If we have that knowledge, then we can do it ourselves'.*

They also used as their reference point the role of doctors. In relation to doctors, some of the senior students felt that their skills were superior to doctors as they were not reliant on diagnostic tests but could diagnose problems by using their manual skills.

The following student considered this as an added benefit for patients:

Obaidul: (4th year male Gono) *'A person with MBBS (doctor), how much is he doing for a patient? An MBBS can provide general treatment but a BSc Physiotherapist can do much better. I won't send any patients for X-ray, MRI or CT scans. We detect problems ourselves, just using our hands. This will be beneficial for the patient economically so he won't feel any social hazard'.*

The reference to social hazards referred to medical practices that were unethical. The older students were all well aware of frequent newspaper reports of patients being sent for batteries of tests they did not need, by doctors who received commission for sending them. In the BSc groups the subject of doctors provoked intense discussion. Although students envisaged a medical role for themselves around impairment needs, they were faced with what they felt was a difficult reality. Some students expressed dismay and indignation, describing confrontations with doctors who were unaware of

their knowledge and skills. Others described particular incidences where their abilities and their contributions to hospital services were beginning to gain recognition. The following description from a final year female student was hailed by cheers and applause from the group:

Humayra: (4th year female BHPI focus):

'Just then the Dean of the medical faculty came in and I went over to speak to him, "Sir, I can't understand if I can see this patient. If I don't see him now then he will get worse". I told him about the patient. He said, "Yes, you can see him"... ..The next day when I arrived in the ward I couldn't see the patient anywhere. He had died.

'...After 6 days, I was called to go to a ward. There was a patient there of Majid Sir (Dean) and I was requested to see him. He didn't call me because I had done a good job (with the previous patient), it was because he realised that the patient needed a therapist. It was a big achievement for me. The Dean of Bangladesh Medical Faculty has called me to see his patient! I was successful!!'

More commonly, however, the BSc students related incidents where they had experienced a lack of respect from doctors, for example:

Rofique: (3rd year male pilot focus group) *'I have experienced how those people (diploma students) can bring our quality down. I was attending a patient of mine and in the meantime a doctor came in and he picked on me. "What are you doing attending a patient? Do you know what has happened to this patient? Where have you come from?" I introduced myself. "Get out! Physiotherapist! Damn!" He behaved just like this... "MI....where have you heard this word from? What does it mean?" I replied "Miocardial in-firction." He was speaking to me in a way as if I committed a sin being there. He didn't expect that I'd be able to say MI or Myocardial infarction. He was totally amused that I said that and especially as I said in-firction. I felt very humiliated.'*

They placed some of the blame for doctors' poor attitudes towards them on diploma level physiotherapy students from the government institute who, in their opinion, were 'bad press' for their profession:

Rofique: (3rd year male pilot focus group) *'Later I realised that it was not the doctor's fault. It was the fault of those diploma physiotherapists working there. Their quality formed that attitude in that doctor's mind. He decided from watching them, he knew their type!'*

Attitudes of degree students towards government diploma students were generally very negative. Diploma students, however, displayed as much if not more ambition to learn as degree students and more willingness to engage in rural communities than degree students.

Students' hospital placements were all based in Dhaka, the capital city. They recounted incidents further afield which they considered to be evidence of a widespread lack of awareness of physiotherapy by doctors. An example of this was given by a female BSc student in her account of her attempts to find a job in the town where she lived.

Swapna: (4th year female BHPI) *'I went to Khulna, in a clinic. That was my relative's clinic. The owner of the clinic was a doctor. He asked us, "What do you do to cure neck pain?" I told him that we would assess the patient first and then would fix an exercise that will reduce the pain. He himself had neck pain but didn't tell us. Then he said "Pain is cured from exercise! Don't say this to anyone else. This kind of talk is not good." He was insulting us very much!'*

8.2.3 Summary

Students on both degree and diploma courses perceived their role to be a medical role based on treatments of individuals. They did however demonstrate a tacit awareness of the wider social needs of disabled people. They were aware of the negative attitudes of society towards most disabled people and of the marginalised position held by disabled people. As potential professionals they also exhibited a general resistance, which was marked in the BSc group, towards the performance of any activities that did not relate to a medical role. Their conceptualisation of disability was strongly linked to physical needs as portrayed in their course documents. Their placement experiences were based, almost entirely, in institutes and reinforced perceptions that disability was about physical problems and treatment. The positive reports of a small number of students, who had been exposed to wider disability issues in the community, highlighted the importance of gaining community experience. The lack of course emphasis on gaining experience in the community appeared to be a significant factor in shaping their outlook.

The different outcomes of the government diploma course and the degree courses, as far as the students were concerned, was highly unsatisfactory. The degree students were keen to establish themselves as medical professionals and the government diploma students who held a more technical status were, in their eyes, giving them a 'bad press'. Students' levels of personal knowledge around community practices reflected their backgrounds. A much greater understanding of community practices was present in students from more rural and poorer backgrounds when compared with students drawn from richer urban environments.

8.3 Section Three

8.3.1 Professionalisation of the Individual

Professional socialisation has been described as the process by which a person acquires the values, attitudes, behaviours, language and jargon of an occupation or profession (Middleton 2007). It is a multi-staged, multi-phased and fragmented process, which does not stop on completion of formal training. It was noted Hart et al. (1990) that professionalisation can occur at the level of an occupation as a whole and at an individual level.

In order to understand the process of professionalisation occurring at an individual level the influences on students were investigated further using a three stage process suggested by Zeicher and Gore (1990). This process was previously discussed in chapter three (Section 3.1.7 and 3.1.8). The stages of the process were anticipatory socialisation, formal training and post qualification. In the anticipatory phase, individuals get a sense of the profession from previous experiences. This also includes images built up from observation (Middleton 2007). The most visible professional healthcare role in Bangladesh is a doctor (Ahmed et al 2011), and this study indicated that the physiotherapist role was perceived by students and their families as being closely related to this role.

Anticipatory and formal training stages of socialisation were discussed in the focus groups and interviews by firstly asking about how decisions were made initially to study physiotherapy. Then, later in the discussion, students were asked to talk about experiences during their placements which were significant to them. Although post-qualification experiences could not be examined in detail, one of the females interviewed had gained several months work experience with an NGO because her final examinations had been delayed due to session jams, and a number of the students transferring to the degree course had already completed their one-year internship. Several of the older students were also working informally in private clinics and therefore experiences influencing them as young professionals could be identified.

8.3.2 Anticipatory Socialisation

In these data there was clear evidence that the extended family were closely involved in the decision to study physiotherapy. This was in keeping with the personal

characteristics of collectivist value systems (Jezewshi and Sotnik 2001). The opinion of leading male members of the family usually carried most weight. Influences from other relatives acting as guardians were also regularly referred to. This was especially so if the relative was a doctor.

The link with medicine was the most decisive factor in making this choice of profession for BSc groups. A small number of the students reported that they had not been accepted to study medicine. Prestige and status were important factors in recommending this as a professional choice for the following student. Employment prospects were also a main consideration.

Mukul: (1st year male BHPI focus) *'I've got an uncle in PG hospital; he's a neurologist. He said to me to take admission in physiotherapy and it's got a bright future as a new profession. There are many medical doctors in Bangladesh who're unemployed. Physiotherapy is much better and is of high status.'*

Humayra: (4th year female BHPI focus) *'My parents think the same that it's like a medical profession but it's a special area of medical profession...like there are dentists ...It's also a special side and if I study this subject then I'll get a job instantly after I qualify. It's a very good subject.'*

A male student on the government diploma course stressed that employment prospects were the strongest incentives to study physiotherapy.

Jahid: (1st year male Gov Dip IHT focus) *'The family thinks about the future prospect. They want us to study a subject which will give us a job in future. They probably thought that we'd get a job after we finish this study and that's why they decided this subject for us.'*

Another factor in choosing was the 'service to the society' orientation. A few students reported that they had chosen physiotherapy personally because of experiences with family members or after observations of a disabled people known to them and they were aware that it involved working with disabled people directly:

Madhab: (1st year male Gov Dip IHT focus) *'I didn't have any idea about Physiotherapy and the senior brother told me that it works with the paralyzed patients. I've got two sisters in our neighbourhood who are about 13 years old. They can sit but can't stand up. They are in lots of difficulties. I thought, if I could treat this kind of people after I finish my study, it would be really good for my country and I myself would also get benefited personally (income).'*

Parental choice was indicated throughout but for females especially in allowing their daughters to enter this profession. There appeared to be a less negotiation with daughters than with sons and more compliance on their part:

Runu: (4th year female Gono) *'I wanted to study microbiology. I came into this course by my parents' choice. I didn't know about the course before taking admission here. I didn't know what physiotherapy was.'*

Sonia: (3rd year pilot focus group female) *'I've heard about this profession from my father. I can't even remember if I'd ever heard the name of physiotherapy before. I didn't know what a physiotherapist did. Anyway, I took admission on his wish'*

Hosneara: (final year female Gono) *'My father had a big accident in 1989. He was in bed for a long time and was taken to Pongu Hospital (NITOR). There he received physiotherapy and after staying there for six months, he was able to walk. He was very excited and relieved that he was getting cured. He got to know how physiotherapy could be effective. That's why he wanted me to study physiotherapy'*

It is sometimes claimed that in Asian cultures women are expected to observe the 'three obediences' namely, to fathers before marriage, to their husbands during marriage and to their sons during old age. Data in this study appeared to support the first point precisely in relation to choice of career and levels of compliance shown by several of the female students who, if they felt any objection to obeying, did not express this the focus group.

8.3.3 Formal Training

According to student accounts, clinical experiences represented a watershed in their professional socialisation allowing students to internalise their professional identity. However the hierarchical authority structure in the hospitals was confusing and fear of authority was not confined to students. Learning how to negotiate the situations they faced was an ongoing challenge not only for them but also for their clinical supervisors who were only slightly older:

Humayra: (4th year female BHPI) *'We have seen the doctors picking up on our supervisors: "Hey, where do you come from? Get out from here! Do you know that I can sue you?" Our supervisor used to hide in the canteen. He never came in sight. He used to hide in the canteen in fear.'*

Having an expatriate teacher as a supervisor (for BHPI students only) they felt, made a big difference to the quality of their clinical experience as the foreigners were shown respect and cooperation from the doctors. Their conclusion was 'foreigners could open any closed doors'. They felt that the variety of different experiences on clinical placements influenced their development most for example,

Rofique: (3rd year male BHPI pilot focus group) *'Mostly, I think environments have influenced us to change. Placement in DMC, NICVD, Orthopaedic hospital and CRP hospital...we've talked to many patients. Actually the environment has changed us. 1st year to 3rd year and in the middle 2nd year environment, if I'm more specific.'*

They felt that gaining experience with patients in both ward and outpatient settings was the most significant factor enabling them to understand and treat impairment related needs. Their experience in these settings related largely to learning how to apply physical interventions and followed standard treatment assessment and treatment procedures used in Western contexts.

8.3.4 Gender Issues in Physiotherapy Education

Gender-related issues were raised by several females in third and fourth year focus group discussions who had decided that gendered aspects of the practical role and any type of sporting involvement was not something that either they or their families were comfortable with. Maintaining a respectful distance from males in all clinical interactions and avoiding familiarity was seen as very important for them and they were very sensitive to the interpretation of their actions. Physical postures and touch were treated with caution because of the risk they posed for females. Cultural interpretations of touch and any suggestion of over-familiarity with male patients threatened their reputation and diminished the respect they commanded. Female students in BHPI felt that some examples set by foreign (British) female therapists could not be followed by Bangladeshi females because of this:

Humayra: (4th year female BHPI focus) *'I've heard many bad comments from patients here as we were involved in sports with them. ... We have to remember that our culture is different to the foreign culture. In your culture, a doctor and a gardener will get the same respect. But in our country, if you get closer to them, they will think you are of low standard and status.'*

The difficulty of treating male patients also related to their honour and assumptions they felt that male patients would make about them which they felt were insulting and dishonouring:

Humayra: (4th year female BHPI focus) *'If we ask about the pain, they will indicate the whole body and say, "Apa (sister), here, massage here!''.'*

All the female students felt that joining in wheelchair basketball and recreational sports activities with patients in the spinal injuries centre were culturally 'out of bounds'. As students progressed through the course, gender issues in more

conservative families became more apparent for the females as they approached qualification. General anxieties began filtering through regarding employment locations that would safeguard their daughters from a high visibility position in public.

Tahamina: (3rd year female BHPI pilot) *'My mum, she's already worried thinking that I'll have to work outside and that she won't be able to keep eye on me. She's worried about where I'm going and what I'm doing. They're worried about the physical contact between the patient and me. They're saying, "Now you're okay as you're working in an institute but when you're coming out of it, how secure are you?"'*

8.3.5 Professional Identity

Most physiotherapy students had formulated strong opinions about their identity as medical professionals. The most popular title they wanted to use was 'Dr'. Reasons for this as given by this final year female student related to the lack of awareness or understanding of physiotherapy. Being recognised in the role of a doctor would encourage patients to attend for treatments.

Shilpi: (Final year female BHPI) *'I think in the Bangladesh situation, it's better to be called a Doctor. Most of the people don't know that physiotherapy is a medical profession. But if you say Doctor, then they'll come to you with their problems. In this situation...awareness'*

This title of 'Dr' was very popular also with national teachers who justified it using America as a reference point.

Tahamina: (3rd year female BHPI pilot focus) *'Just a few days ago 'Obaidul Sir' (Physiotherapy course co-ordinator) told us that the American Physiotherapists were permitted to use the Dr title by their name and so we were allowed to write Dr. by our names...'*

The degree students were all aware that this title was utilised by Indian physiotherapists and older physiotherapists who were working in Bangladesh. A small number only expressed that they were not so comfortable with this title and were aware that this practice was not officially allowed in Bangladesh. This occurred in interviews only.

Alam: (1st year male Gono) *'There are many students in this institute who are in favour of writing Doctor and want to write "Dr" by their names thinking that many will recognise us by that title. But if people ask us "A doctor of what?" we can't answer...we don't have permission to write "Dr" by our names.'*

One of the females also expressed this view. Lengthy 'session jams' had extended her course and she had therefore commenced her employment alongside a male

expatriate physiotherapist from whom she had learnt several skills and who had possibly influenced her perception of her professional identity.

Pretty: (Newly qualified female NITOR) *'I feel proud as a physio. I don't feel comfortable to call myself a doctor. Physiotherapist recognition is most important (honourable) to me. I don't think that my honour will increase if I write doctor title.'*

She was working for a small NGO for survivors of acid attacks. She described her practical skills in great detail working with females who were victims of acid attacks and described her role enthusiastically. She felt she played a key role in restoring function and the confidence of victims of these attacks. She stressed the importance of attending to the psychological needs of her patients' alongside their physical needs and displayed a clear understanding of the devastating impact of the injuries she treated. She recognised that physiotherapy skills were valuable and lacking in Bangladesh.

Arguably for female students, becoming 'medical professionals' added value to their marriage prospects. This was unanimously agreed by the males and strenuously denied by the females when the subject was raised in the discussion:

Main Researcher: (Question addressed to females) *'Do you think the doctor title is better for marriage?'*

All male students (Gono): *'Yes !!'*

Dilip (4th year male Gono focus): *'Our girls are going to be doctors so we'll have to find doctor husbands for them (all laughing)...The market is so hot for doctors. So hot!'*

Main Researcher: (Question addressed to females) *'If you say you are a 'physiotherapist' is the marriage status lower for you then?'*

All female students (Gono): *'No!!!'*

8.3.6 Future Employment and Professional Development

The diploma physiotherapy students were also quite distinct in their ambitions when compared to the BSc students. Although both groups were very keen to have opportunities to learn and gain greater qualifications, the BSc students preferred to work in a city location or go abroad, whereas the diploma students were prepared to work anywhere they could find a post. Also one diploma student expressed his desire to work in a village location:

Iqbal: (1st year Gov Dip IHT) *'After I qualify I'd like to work in my village or in any village where people are helpless, not receiving treatment'.*

The government diploma students were very intense about wanting to learn and were disappointed there were no physiotherapists on their teaching staff. They anticipated that their role would entail carrying out prescriptive treatments ordered by doctors but unlike the BSc groups raised no objection to this. The major concern of the all-male government diploma group interviewed was to secure employment. Some in this group mentioned that their families were making sacrifices for them to enable them to access physiotherapy training. The wealthier BSc students were critical government diploma students who they regarded as their inferiors. The BSc students mostly wanted to work in or near to the capital city:

Rofique (3rd year BHPI pilot focus group): *'One problem is that, after passing, we, the qualified people (emphasized) want to establish ourselves in Dhaka (the capital) or we want to stay around Dhaka...It's likely that in Dhaka they're (diploma students) not brave enough to compete with us. These low quality people are going to other districts where they're "all in all" in physiotherapy'.*

The desire to be urban based reflected the backgrounds of many of the wealthier students. They mentioned the illiteracy and lack of understanding they would face in rural areas and the challenges this would present them e.g.

Selina: (1st year female NITOR) *'People in the cities are much more aware than the villagers so when I'm trying to set up a clinic in the town, I won't face much difficulty. But when I go into a rural area, in a village, they don't understand. They are very illiterate and they don't understand what physiotherapy is'.*

The extended family appeared to have most influence on both decisions around entry into physiotherapy and employment options afterwards and there was a strong gender element running throughout. For females this influenced the roles they felt comfortable with. They expressed preferences for roles which minimised mixing and physical contact with the opposite sex. Females wanted to work with female patients or children and also thought that lecturing was also an appropriate role for them. Male students were preoccupied with various prospects for income generation and some expressed fears around financial insecurity:

Mukul: (4th year male BHPI focus) *'Now we're in the final year but sometimes I feel like if I can earn 8-9 thousand taka from any other profession then I'll leave this profession. I've thought about this many times..'*

Sohrab: (1st year male BHPI) *'When I'll come out after 5 years, certainly my parents will not support me financially. I'll have to have a job. So, I certainly need to have a post. I need a government job. Everyone is talking about this issue.'*

The same concerns were common at all levels interviewed and the similarities in opinions around the general prospects of comparable groups were evidence of the intense networking which occurred.

Regarding their further development as professionals many students wanted to study to Master's level. Going abroad to study and then live was seen as an attractive option by both male and females. This included first year students who had decided their career progression, for example :

Selina: (1st year female NITOR focus) *'And now we have a target to complete graduation, then doing a job for a while and then going abroad.'*

Students felt that going abroad would mean a loss for their country. A number anticipated that the material gains to be had would be a decisive factor in their decision not to return.

Selina: (1st year female NITOR focus) *'Who's having the loss? My country. Our brighter students are going abroad for better results. We're getting good facilities when we go abroad and that's why we're not coming back to the country.'*

8.3.7 Occupational Professionalisation

In all focus groups students were concerned about the lack of government recognition for their professional status. They identified needs for government registration, post creation, and standardisation of training and proper regulation as their main needs. Degree students regularly referred to Western contexts and India as reference points for setting their expectations for their profession in Bangladesh. They were united in wanting the government to recognise physiotherapy and value the contribution they felt they could make.

Akheel: (1st year male Gov Dip IHT) *'Anyway I want to say that physiotherapy is valued a lot in other countries, especially India, and other countries are placing importance on physiotherapy. Then why are they (the government) not giving it in Bangladesh? We're experiencing that they are neglecting us.'*

For degree students, professional recognition entailed the creation of posts at a higher level than the technical level posts, which they felt did not honour their professional

status. The establishment of opportunities for further education was also considered to be an important step in establishing physiotherapy as a profession.

Selina: (1st year female NITOR focus) *'I think it's mostly the government's duty to ensure the required honour for a physiotherapist, to create a first class post and to set up an institute for higher education. These are very urgent.'*

Degree students wanted educational opportunities to study physiotherapy at Master's level in order to bolster the status of the profession with recognised qualifications :

Selina: (1st year female NITOR focus) *'It should not be that I'd be stopped at graduation level. I'll have to acquire more and more knowledge. That's why I feel the necessity of higher education (Master's).'*

Pretty: (Newly qualified female NITOR) *'It should be there if we want to develop the profession. All are going abroad for Masters as it's not in Bangladesh.'*

Researcher: *'If I ask "What level are you at?" and you say, "I'm Master's", what's the difference?'*

Pretty: *'Difference is that I have more knowledge, the depth of knowledge is more. It doesn't matter what people say, what I know and the service I can give are more important to me.'*

One feature of the focus groups when compared across the different sites was the commonality of these ideas across sites in all except students from the newest intake in NITOR. This suggested that intense networking in all but the newest students was occurring to mobilise a collective demand to lobby the government. This was in keeping with the strongly political nature of student activities in Dhaka University. A common opinion voiced was regarding the source of opposition. The medical profession was seen as an opponent who wanted to prevent the establishment of professional status and maintain tight control of the medical field.

Obaidul: (4th year male Gono) *'There are so many problems in our society to reach our goals or expectations. Actually, in the medical sector, there are some orthopaedicians (Physical medicine), I think they're one of our barriers. They don't want our physiotherapy to be established.'*

Low levels of trust expressed were also linked to the belief that control of the financial market in healthcare was behind the reluctance to support their intended progression towards autonomy:

Dilip: (4th year male Gono focus) *'Ours is a poor country. Doctors are taking advantage of this situation and trying to dominate the physiotherapists so that people and government don't get to know about them. They're always scared to lose their market. That's why they're still holding the power to dominate us.'*

Rahman (2009) characterises the dominant cultural pattern in Bangladesh as being hierarchical where individuals identify strongly with groups and there is a low level of trust between groups and high levels factionalism. He attributes this to 'an uneven race for scarce resources by numerous contenders who are averse to following the rules of the game' (Rahman 2009, p.2). The negativity around the motives of medical professionals was evident within the student groups and the hierarchical nature of the relationship between diploma and degree level students also exemplified this trait.

8.3.8 Summary on Professional Socialisation of Physiotherapists

Professional socialisation of physiotherapists at an individual level was influenced in the anticipatory phase by the strong association made between physiotherapy and the medical profession. Decisions regarding both entry and progress in this career were based on systems of family and kinship operating at collectivist rather than individual levels.

The high status and potential for employment opportunities this new profession was assumed to offer influenced the choice of physiotherapy as a career. Formal training experiences were largely related solely to impairment needs, with limited exposure to wider social needs of disabled people at a community level. However, students with exposure to community needs were enthusiastic about the value of the wider range of interventions they had experienced.

Preferences around work locations and role preferences largely reflected students' backgrounds and gender. Government diploma level students from more rural and less wealthy backgrounds were more willing to work in rural locations and exhibited a tacit understanding of cultural and social aspects of disability in rural locations. Lack of standardisation in physiotherapy professional education by the maintenance of two quite different courses (government diploma and BSc) meant that a two-tier system was developing amongst both qualified physiotherapists and students.

8.4 Section Four

8.4.1 Impact of these Findings in Relation to Needs of Disabled People

Several factors emerge from these findings which have relevance to the development of professional education for physiotherapists in Bangladesh.

The Declaration of Principle on Education (WCPT 2009) includes the statement that curricula for physical therapy education should be relevant to the health and social needs of the particular nation. WCPT's (2009) Ethical principle 8, also states, 'Physical therapists are obliged to work toward achieving justice in provision of health services for all people'.

In this study, knowledge from users speaking out of their experience within the local context and environment, indicated that disability was experienced as a multi-dimensional experience. Theory and practice in all physiotherapy courses prepared students almost exclusively for institutional employment, and was based upon an individual model of disability. Nevertheless, several students in the government diploma group exhibited an in-depth knowledge of cultural and community practices based on their backgrounds. Although recognition and attention to impairment needs was recognised in the courses as being important, the conceptual separation of impairment and disability would have enabled an integration of the rich personal knowledge they exhibited, with other forms of professional knowledge. Thus, the formal course content around disability aligned poorly with accounts related by service users (These were presented in chapter five).

This finding suggested that course content would benefit from the inclusion of e.g. Priestley's fourfold typology of disability or Thompson's illustration of discrimination (Chapter 2, fig 2.1). These would provide a stronger theoretical component for this of professional preparation. Such a change would facilitate an understanding of approaches underpinned by a rights-based perspective of disability e.g. discussions around CBR. It would also foster a greater engagement of the emerging professional group with the vibrant disability movement occurring in Bangladesh. An appreciation of the socio-political aspects of disability could result, for example, in better liaison with NFOWD, whose initiatives, working with Government, have resulted in changes in the disability legislation. This collaboration may also have an impact on government policy on post creation for therapists in government hospitals, a topic of intense concern to students.

It was noted in chapter three, that in order to build an appropriate knowledge base for establishing clinical practice in healthcare, a working knowledge of practice epistemology was needed (Richardson et al 2004, p.2). Appreciating the validity of

sources of knowledge that could inform the practice knowledge base was an important consideration. In addition to propositional knowledge, sources of non-propositional knowledge include professional craft and personal knowledge (Higgs and Titchen 2000) and knowledge from the local context and environment (Rycroft-Malone et al 2004). In order to achieve the transition above, the introduction of a practice epistemology would have been highly advantageous. Equipped with such an understanding, educators could have aligned courses content much more accurately with social realities students were tacitly aware of.

Two key goals of professional education have been identified, namely the preparation and professional socialisation of students for their designated profession, and the fostering of social responsibility to enable graduates to make a community contribution (Hunt and Higgs 1999, p.166). By introducing a wider understanding of disability it is possible that changes in practice would emerge. Such changes may possibly, not only augment interventions in acute hospital settings but also foster greater support for community-based approaches to disability.

8.4.2 Changing Course Content

It was reported in chapter five that psychological support to strengthen a positive identity in light of the overwhelmingly negative attitudinal environment was highly valued by disabled people. However, the absence of community placement experiences in three out of four of the participating institutes denied students the opportunity to witness the impact of physical and attitudinal barriers on disabled people. Interventions at an individual level only have previously been acknowledged in South Africa by Cornielje (1999) as an obstacle in delivery of appropriate effective rehabilitation services. In Bangladesh, a strong focus on impairment and treatment interventions coupled with an inattention to subjective experiences did little to engender the professional goal of social responsibility in students. The need to include CBR into professional physiotherapy education in Bangladesh was indicated, particularly in light of other changes taking place in the field of disability. A number of other contexts in which physiotherapy education has been introduced have already made this inclusion. Dawson (1997) indicated that this had been included in the undergraduate programme in Bethlehem University. It is notable that in South Africa,

the school at Western Cape has based its entire curriculum on a CBR model (Twible and Henley 1993).

The development of a role in CBR assumes a comprehensive understanding of the social dimensions of disability and goals of CBR. The possibility of developing a more comprehensive understanding of disability is already present as projects approaching disability as a rights-based issue, (applying the CAHD strategy), are already taking place in Bangladesh. Including social perspectives of disability in professional physiotherapy courses would facilitate the development of a continuum of service provision from grass roots to tertiary care. Its inclusion would enable students to appreciate the place of healthcare services in relation to the wider panorama of development. By including an understanding of disability as oppression, students would simply have been provided with a theoretical framework which allowed them to utilize personal knowledge.

Twible and Henley (1993) suggested that in CBR, the knowledge and skills required by physiotherapists include not only provision of therapy but management, teaching, networking, organisational skills and health promotion. WCPT (2009) also identified a role for physiotherapists as consultants, supervisors and policy advisers. However, these elements were absent in three out of four of the courses offered.

8.4.3 Role Socialisation

Students in this study identified themselves closely with medical healthcare professionals with little role to play in the wider social arena. Anticipatory socialisation experiences reported by the students in this study identified the collective nature of decision making in Bangladeshi families and suggested that, from the outset, physiotherapy was seen as a medically related profession. In the absence of an established physiotherapy profession, medical doctors represent the largest qualified healthcare group (Table 3.3 shows the density of all healthcare providers), and were possibly a major influence in shaping ideas around anticipated professional behaviour. The high social status of medical professionals and other potential benefits appeared to be a factor in the choice of physiotherapy as a profession.

A number of factors suggested that the emergent professional group were becoming increasingly resolute in their desire to establish a pseudo-medical role. These included

a tangible sense of resistance to the performance of other roles and a strong desire to identify physiotherapy as a 'branch of medical science'. The biomedical content and focus of treatments in professional courses together with formal training experiences based solely around hospital experiences did little to change this expectation and much to consolidate it. Additionally, the small number of older national physiotherapists (both teachers and practicing physiotherapists) were seen as role models and were proactive in promoting this role formation.

Socialisation includes explicit and covert ways in which new members of a profession learn to be like other professionals and to be accepted members of the profession (Richardson et al 2004, p.210). A strong interest was shown by all the BSc groups in professional physiotherapy activities in India and America, using these groups as frames of reference. Thus, a number of internal and external factors were influencing the 'role taking' and the 'role making' activities involved in shaping professional practice, as described by Cusick (2001) (Section 3.1.8).

These findings around socialisation processes suggest that if CBR is to be introduced effectively as a role option for professional physiotherapists then students' expectations around professional role will need to be addressed early in the training process and carefully guided by provision of appropriate training experiences. Richardson (1999) noted previously that there was little in the literature to indicate professional socialisation had been of any interest to educators. Given that it is estimated that 70% of disabled peoples physical rehabilitation needs could be handled at the community level whilst the remaining 30% require specialist interventions (Thomas and Thomas 2003) the need for greater appreciation of the importance of addressing professional role socialisation processes is highlighted by these findings.

Twible and Henley (1993) suggested that preparing therapists to change practices from traditional institutional services is a professional imperative. However, in the situation of Bangladesh there is little to change from, as traditional services have yet to be established. A need for referral to specialist services has also been identified in CBR and this means that the development of specialist institute based physiotherapy services also cannot be ignored within the context of Bangladesh. Therefore given that the development of institutional services will remain important for some time, attention also needs to be given to fostering a supportive role physiotherapists could

have in the community. It is important to note that the role envisaged for professional physiotherapists in CBR (Twible and Henley 1993) often utilises their expertise in the area of impairment and this knowledge is largely gained from clinical experience in specialist institutional services. This means that alongside institute based services, an understanding of the principles and practice of CBR is necessary if a transition into appropriate roles in CBR also is to go ahead.

8.4.4 Choice of Trainee for CBR

Work in rural environments requires practitioners to be equipped with the appropriate knowledge and skills necessary. Maas (1997) highlighted the need of professional physiotherapists in CBR to be able to promote empowerment. The oppression of disabled people is experienced as a phenomenon of power where relationships are experienced in terms of superiority and inferiority (Charlton 1998). Large gaps in status between therapist and user are unlikely to be empowering especially in a strongly hierarchical society.

As empowerment is a key component of the CBR strategy (WHO 2010), the backgrounds of the diploma students suggested they may be better equipped than wealthier urban students to work in CBR. It is significant that in Palestine, when establishing baccalaureate courses for physiotherapists, students were drawn from all geographical regions of the country and a CBR module was included in the course (Dawson 1997). Government diploma students in this study were more willing to work in rural areas than graduate students and they also had greater working knowledge of community practices. These factors suggest that selecting students from different parts of the country for training would increase the likelihood of their returning to work in these areas and result in greater access to services in rural areas.

The present government diploma course strongly emphasised the use of electrotherapy. Peat (1990) suggested that sophisticated technology and highly specialised care is not required by the majority of disabled people in both a developed and developing context. A greater focus on functional physiotherapeutic training would therefore be more appropriate preparation for this group. A greater emphasis on problem solving rather than carrying out prescriptive practices would also equip

them more adequately for this role and facilitate the integration of personal knowledge into practice.

Richardson et al (2004, p.208) have previously highlighted the need for practitioners to 'replenish the stock of knowledge on which practice is based, so that it reflects the contemporary needs of health care and can ensure quality and cost effectiveness to serve all clients'. Three BSc curricula examined followed physiotherapy training used in the 1980s in the UK with no evidence of updates. These were possibly compiled from documents used in the first attempts to introduce physiotherapy education into Bangladesh after the War of Liberation. This pointed to a need for updating of these courses.

Hammell (2006) maintains that therapists play an active role in maintaining and perpetuating disabling environments or an active role in changing them. In order to begin to address the inequities around marginalisation of disabled people consideration is needed around the appropriate practitioner model to adopt. A capacity model focusing on the empowerment of users (Chapter three, section 3.1.4) would be appropriate to consider. Features of an interactional model (Section 3.1.5) including, for example, the development of social ecologist perspectives, and situational responsiveness also hold potential value in this context. The introduction of these approaches necessitates attention to healthcare educator training.

8.4.5 Gender Considerations

Female students from conservative backgrounds were reluctant to cross what they considered to be acceptable gender norms in their physiotherapy roles. This suggests that greater attention to gender issues would be beneficial in preparatory education. Numerically all the courses displayed lower intakes of female students compared to males but no rationale for this selection was given. All professional course leaders were male. Selection of students needs to be investigated further if issues around gender equity in service access are to be addressed.

8.4.6 Chapter Eight Conclusion

The findings from this section of the data analysis suggest that the present day courses for professional physiotherapists, based solely on an individual model of disability and focused on treatment have not provided an understanding of disability which aligns

with the social reality within this context. The addition of teaching around social, political and cultural aspects of disability will facilitate a better alignment of interventions with perceived needs of service users. Effective collaboration with development efforts, underpinned by a rights-based approach to disability, is being hampered by outdated course content and limited exposure to changes in international thinking and political developments around disability. Gender stratification requires specific attention on professional courses. The findings point to the need for the development of education for educators, which includes an understanding of the importance of role socialisation. An understanding of practice epistemology would also allow personal and contextual knowledge to incorporate into the knowledge base informing clinical practice. Government diploma course content would benefit from review in order to maximise the potential in this group of students for the benefit of disabled people.

Chapter Nine

9.0 CONCLUSIONS

This chapter presents the conclusions of the research. After reviewing the purpose of the research, findings related to professional physiotherapy education and training of related healthcare workers which are of potential benefit to disabled people in Bangladesh, are summarised. A number of theoretical conclusions are then drawn. Limitations of the study and suggestions for further research are then identified.

9.1 Purpose of the research

This study was designed to answer three research questions;

1. What knowledge, beliefs and expectations around disability typify users of therapeutic services in Bangladesh?
2. What beliefs do student physiotherapists and related healthcare workers hold around the needs of disabled people and their own particular role in providing intervention, and what is influencing this perception?
3. Are there identifiable adjustments in professional education and training of related healthcare workers around disability that might be beneficial for disabled people in this social context?

The answers to the first two questions were intended to inform the third. The purpose of the third question was to allow the research findings to act as a resource for educators of the different provider groups. The research questions were based on two premises, namely, that physiotherapy practice needs to be underpinned by a sound theoretical knowledge base and, in order to demonstrate 'fitness for purpose', disability services must satisfy the perceived needs of service users. Transcripts of semi-structured interviews and focus group discussions were finally produced in English. Twenty-seven transcripts from users who had accessed physiotherapy services in the past year were analysed to establish a composite knowledge base around user experiences and beliefs. Thirty-six transcripts encompassing six provider groups were then analysed. Each provider group analysis was then compared with the composite user group analysis and emergent findings used to inform educational theory.

By comparing perceptions of user experience and articulated needs around disability with those of provider perceptions, levels of congruency could be identified. Discrepancies highlighted areas where adjustments in professional education and training around disability might be of benefit to disabled people within this context. User findings were reported in chapter five of this thesis, and provider findings in chapters six, seven and eight.

9.2 Summary of findings around the experience of disability

The lived experience of disability as reported by service users involved a complex mix of factors relating to culture, religion, gender, economic status and the political environment. Negative discrimination was experienced at personal, cultural and structural levels. These findings indicated that disability was multi-dimensional in nature and aspects of this experience related to both materialist and idealist explanations of disability.

Service users indicated that whilst treatment needs relating to impairment were important, rehabilitation needed to become orientated to socio-cultural domains and needed to address both material conditions and social relations.

9.3 Diversity in experiences of different provider groups

Participants in provider groups included workers from all training approaches currently in use in Bangladesh which equip workers with physiotherapy skills to intervene in the lives of disabled people. Provider groups consisted of two impairment focused groups (Leprosy Physiotherapy Technicians and Developmental Therapists), two groups of Community Based Rehabilitation workers trained using different conceptual models of disability, and two groups of students preparing to work as professional physiotherapists (BSc and Diploma groups).

Although all groups studied provided physiotherapy as a main component of their role, they worked in different locations in both rural and urban settings. These included hospitals, rehabilitation institutes, rural clinics, schools and homes. This gave them varying degrees of proximity to the lives of disabled people. Training was underpinned by a rights-based development approach to disability in only one of the six provider groups studied. This group's activities aligned closely with the wider needs identified by service users. Their training utilised a three-tier strategy known as Community

Approaches to Handicap and Development (CAHD) (Appendix 3). These community workers were employed in development projects which were geographically spaced over the country. They provided basic physical rehabilitation services which were accessible and referral services to secondary or tertiary care. A distinctive feature demonstrated by this group of workers related to a focus on the needs of the community as a whole (rather than solely on the specific needs of an individual) and the integration of impairment and disability issues into development assistance.

The approach used to train these workers was part of a wider strategy which challenged disablist practices at personal, cultural and structural levels and included rigorous attempts to promote the rights of disabled people. The workers were trained using a capacity building/empowerment model and related to families informally. Social norms in gender stratification were maintained in dealing with all service users.

The second type of community based rehabilitation workers studied, Community Based Rehabilitation Technicians, were trained utilising an 'Institute Extension Model' (Thomas and Thomas 2003). Training was mainly institute-based and these technicians worked in community sub-centres largely administering treatment applications. A small number of home visits were made if users were unable to attend sub-centres. This group participated in awareness-raising activities in madrasas and schools in which they promoted biomedical explanations for impairment and informed of treatment availability. Findings suggested that this group's activities had a limited impact on structural and attitudinal barriers faced by users. Preponderance of male technicians also restricted access to females and the development of services for children.

Two provider groups in this study were trained to address the needs of users with specific types of impairment. The curriculum content of both groups was based on an individual model of disability and both utilised a wellness model of practice. The first of these groups, leprosy physiotherapy technicians, worked both hospitals and rural clinics and were technically, highly competent. Rigorous awareness-raising campaigns in mosques, schools and communities had ensured that an understanding of the cause of leprosy was established in areas where these technicians worked. These appeared to have played a significant role in reducing attitudinal barriers to inclusion for persons affected by leprosy. Some of the technicians also utilised their personal knowledge of

the culture and community to devise ways of reducing discrimination at an individual level. However, as a whole, the technicians were largely unaware of strategies that could be utilised to address structural imbalances impacting people affected by leprosy. Greater attention in training to gender stratification could also enhance benefits to females affected by leprosy.

Developmental therapists constituted the second group of providers whose training focused on one type of impairment. They addressed the therapeutic needs of children. Developmental therapists participating in this research worked in a child development clinic and a school for disabled children (Appendix 8). Interventions offered strong practical and psychological support to mothers of disabled children. However, despite the key role fathers played in decision making there was little evidence to suggest that their needs were attended to. A strategy was needed to ensure information needs were routinely addressed in a culturally sensitive way.

Validation and standardisation of training courses for developmental therapists would enhance the effectiveness of this group. The inclusion of social model perspectives around disability in training would heighten awareness of barriers to inclusion faced by families with disabled children and help generate more strategic responses to these.

Professional physiotherapy courses included both BSc and diploma level students. BSc students demonstrated expectations of employment in city institutes and private practices. Professional socialisation processes were aligning this group with the medical profession and professional boundaries between the two professions were unclear. Although BSc physiotherapy education lasted up to five years there was little evidence that this group would provide tangible benefits to the wider disabled population, most of whom were unable to access their services. These findings raise ethical issues around the present direction of professional education for physiotherapists in Bangladesh. There was a professional imperative to incorporate relevant community based rehabilitation experiences into physiotherapy courses.

Government diploma level physiotherapy training was mainly focused on the prescriptive use of technological equipment and the content of this course would benefit from review. Although diploma level physiotherapists were potentially the most suitable group to be of benefit to community-based rehabilitation projects, this

opportunity was not being grasped. The high numbers of males in both professional physiotherapy courses and issues raised by female students around gender stratification indicated that attention to this area was called for in professional courses.

9.4 Theoretical Conclusions

9.4.1 Conclusion 1: Reframing Notions of 'User' in a Collectivist Society

The research took place in a patriarchal, hierarchal society which, although showing signs of transition, held a largely collectivist value system. This highlighted the need to re-align content of courses with collectivist society values.

Frames of reference used by users and students related consistently to family and community expectations. Failure to meet expectations met with strong social sanction. Most of the incidents reported by both users and students in the data could be linked to these collective units. Had the notion of an 'individual user' been replaced by that of a wider family and community as 'collective user', in keeping with collectivist society values, then intervention outcomes may have been very different. In view of the historical influence of the UK in Bangladesh, it could be argued that the import of individualistic proclivities from western contexts was partly instrumental in producing the difficulties encountered. A possible way of overcoming problems engendered by transfer of knowledge and concepts cross-culturally is the utilisation of 'cultural brokers', i.e. persons who are knowledgeable about both societies and have the ability to facilitate such transfers in culturally meaningful ways.

9.4.2 Conclusion 2: Need for an Understanding of Practice Epistemology

During the interview process all participants drew on their personal knowledge of the culture and community. An understanding of the importance and validity of this source of knowledge needs to be recognised in order to build an appropriate knowledge base for the context of practice. Although the importance of a practice epistemology has been highlighted in healthcare literature, (Section 3.1.3), its absence was much in evidence in the research findings. Introduction of a working knowledge of practice epistemology in the education of healthcare practitioners is strongly supported by these research findings and warrants particular attention.

9.4.3 Conclusion 3: Recognition of the Importance of Role Socialisation

In this study the impact of anticipatory and formal socialisation experiences on perceptions of both professional role and the role adopted by other healthcare providers was marked. This finding highlighted the importance of this topic generally and demonstrated the need for professional healthcare educators to understand and guide the socialisation of students towards a socially responsible role which takes into account of the health and social needs of the nation.

9.4.4 Conclusion 4: Addressing Gaps in Disability Theory

In Bangladesh professional physiotherapy education is underpinned solely by an individual model of disability. As a consequence these courses have failed to equip the emerging group of professionals with an understanding of the rationale for Community-Based Rehabilitation. Professional groups also display a marked lack of engagement with a rights-based, development approaches to disability gaining momentum in Bangladesh. According to Thompson (2001, p11) 'an intervention with a disabled person which fails to recognize the marginal position of disabled people in society runs the risk of providing the client with more of a disservice than a service'. The findings presented suggest that theory around disability needs to become a specific course strand in professional education of healthcare providers. A taxonomy of disability which facilitates an understanding of the complex nature of disability was suggested by Priestley (1998). (This was discussed in chapter one, section 1.5.1). Adopting the fourfold typology of disability proposed as a teaching tool, would align disability theory more adequately with the realities reported by disabled people and would facilitate the development of more adequate strategies for intervention.

A complementary teaching tool is provided by Thompson's (1997, p.21) illustrative model showing the interplay of personal cultural and structural levels of society (This is shown in fig 2.1, section 2.1.1). Its use would facilitate a greater understanding of the discriminatory nature of disability in healthcare practitioners.

In chapter three it was argued that one of the major influences on professional physiotherapy education in Bangladesh comes from the UK's professional physiotherapy body, the CSP. This has retained an individual conceptualisation of disability (Section 3.2.2). In 2008, CSP's international advisor drew attention to the failure of the CSP to engage with the social model of disability, and called for

promotion of awareness of this model (CSP 2009). In light of the value being placed on internationalisation in higher education, and international changes in thinking and legislation around disability the theoretical tools suggested above merit further attention.

9.4.5 Conclusion 5: Providing Flexible Routes to Professional Qualification

According to the Declaration of Principle on Education by WCPT (2009) curricula for physical therapy education should be relevant to the health and social needs of a particular nation. The recommendation is that entry-level education for physiotherapists should be based on a minimum of four years university or university-equivalent studies. This study showed that a high calibre of technician (Leprosy Physiotherapy Technician) could be trained and these workers were fulfilling roles which qualified physiotherapists were unwilling to perform. This group expressed a strong interest in accessing accredited learning pathways in order to develop as professionals but the absence of such pathways was prohibitive. This situation could be accommodated by a more flexible policy from WCPT. Schemes that provide incremental routes to professional qualification may have a valid place in countries such as Bangladesh and would do much to enhance the low status of related healthcare workers. However, findings from professional groups suggest that ethical issues around the accessibility and sustainability of services to marginalised groups needs to become and remain central in any discussion around professional development.

9.5 Limitations of this study and suggestions for further research

A number of limitations were evident in this study. Firstly, the study cannot be considered to represent the views of all disabled people in Bangladesh. It captures only the perspectives of a small number of disabled people who have accessed services which include the provision of physiotherapy. The vast majority of disabled people in Bangladesh have no access to services which are appropriate for their needs. Research with this group would more accurately portray the lived experience of disability within this context.

Secondly, the study was also limited by the fact that, as a foreigner with a western world view, I was technically an outsider. The enhanced status of my position did, however, facilitate access to interviews that may not otherwise have been possible.

Thirdly, the study was limited by lack of available finance to fund a backwards-forwards translation of selected parts of the data. This could have been used to capture more nuanced meanings present in the raw data and to consider other conceptual equivalents. This would have strengthened rigour in the analysis

A number of areas for further research were identified by during this study. Firstly, there is limited acknowledgement of the potential informed Muslim leaders have in influencing community attitudes towards disabled people. In this study two instances of successful health education campaigns enlisting the assistance of religious leaders were noted, one in the UK (Section 2.4.4, Appendix 1) and one in Bangladesh (Section 5.2.4, Appendix 7). Further investigation into how these influences could be developed further is indicated in light of claims that it is possible to identify a justification for a rights approach to disability in the Qu'ran, based on specific human rights in Islam. According to Maqsood (2006, p.129) these include the right to work and education, the right to dignity and the right not to be abused or ridiculed.

Several factors currently impact on the education of health professionals including the changing healthcare arena. Higgs and Hunt (1999, p14) have proposed that the interactional practitioner model (discussed in Section 3.1.5) will enable future healthcare practitioners to operate effectively within local and global contexts. A number of features of this model were pertinent to the findings presented, for example, the role of the therapist as a change agent who demonstrates professional responsibility in serving and enhancing society and as a social ecologist i.e. one who is active, proactive and responsive within the healthcare environment (Higgs and Hunt 1999, p15). The relevance of these features to the wider changes occurring in the field of disability suggests that this practitioner model should be explored further.

Finally, a further area suggested by the findings in this study which warrants further investigation concerns role socialisation of medical professionals. It was not the purpose of this research to address this topic, but frequent references to this group highlighted this is a significant topic of interest to all stakeholders in the disability field.

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Appendix 1

LEAFLET : ISLAM AND CHRONIC PAIN

Information Leaflet for Muslim Patients

Bradford Teaching Hospitals **NHS**
An NHS Foundation Trust

Taking Care Of Your Health:
Islam & Chronic Pain
Information Leaflet for
Muslim Patients

The Holy Quran states "Allah intends for you ease and does not intend for you hardship" (Surah Al-Bakarah 2:185)

As trustees of our body, we have a duty to maintain its physical well-being, and to rehabilitate ourselves if we become ill or disabled.

Islamic teaching is supportive with the idea of physical rehabilitation. This benefits the rest of the abilities that Allah has preserved for us, and increases their potential.

Obligations of Family & Relatives

Why should I struggle with daily tasks when my family are willing to help care for me?

Islam sees the care of the sick, elderly and disabled as a religious duty. It is regarded as a virtuous act which is greatly rewarded by Allah.

However, Islam encourages independence in our daily life and we should not be an unnecessary burden on others. There are many teachings from Prophet Muhammad's (Peace Be Upon Him) life that illustrate this:

Once Abu Bakr (Radiyallah anho) was riding a camel, the reins of the camel dropped from his hands. He came down from the camel to pick up the reins. He was asked why he had not asked someone else to pick up the reins for him. He said, "My Prophet has ordered me to do things for myself, and not beg anything from any human being."

Prophet Muhammad (Peace Be Upon Him) has taught us to take steps to maintain and improve our independence. It is important to fulfil our faith obligation by working with health care staff, doctors, nurses and physiotherapists and making good use of the resources and time they can offer.




Review date: Dec 2005

Authors: Mohammed Arshad – Muslim chaplain
Gill Fletcher – Senior Physiotherapist, Rehabilitation Team

MID Ref: 04111118

Islam & Well-Being

What does Islam say?

It is a religious obligation to take care of our health. Our bodies and minds are in trust from Allah (God) and this means responsibilities for each of us for ourselves. After faith, health and well-being are understood to be the greatest blessings to have been given to people and as such they are accountable to Allah.

It means knowing more about how our bodies function, and how it can become ill. The knowledge of certain health care professionals such as doctors, nurses, physiotherapists and psychologists can help us to care for ourselves. They help us to fulfil the blessings and trust from Allah in the care of our body and mind.

We are responsible for our bodies, and if we fail to do so, we will be questioned about it.

The Prophet Muhammad

(Peace Be Upon Him) said "A servant of Allah will remain standing on the day of judgement until he is questioned about his age and how he spent it, and about his

knowledge and how he utilised it, about his wealth from where he acquired it and about his body as to how he used it". (Tirmidhi/Behaqi)

All doctors including those from the Islamic tradition agree that there are two ways to look after health:

- preserve health of a healthy person, both body and mind.
- Restore health where possible through medication, treatments and rehabilitation.

Understanding pain, symptoms & what they mean

"Pain in the body is often a signal of something wrong, which we can cure by remedial measures. Our duty is to find out our own shortcomings and remedy them. If we try to do so in all sincerity of heart, Allah will give us guidance." (64:11) (A. Yusuf Ali).

This means that this type of pain known as acute pain can often be treated by using pain relief treatments. For example using paracetamol, acupuncture and massage.

Seeking Treatment

I have faith that Allah will heal me. Why seek treatment?

A companion asked Prophet Muhammad (Peace Be Upon Him) "O Prophet of Allah, when we are ill should we seek treatment or should we seek faith in Allah and not seek treatment as Allah will cure us?" Prophet Muhammad (Peace Be Upon Him) replied "Oh servant of Allah-you must seek treatment for your illness as Allah did not create a sickness but has created a treatment for it (except old age)." (Bukhari).

According to this Hadith Muslim scholars agree it is the Prophet's (Peace Be Upon Him) Sunnah to seek treatment.

Allah has directed that we seek treatments for our illness. This means seeking help and advice from doctors and other professionals who are trained in a particular speciality such as physiotherapists and psychologists.

Rehabilitation

What does this mean for me?

Physical rehabilitation means it is possible to become more physically independent. This will mean doing a regular, daily, gentle stretch and strengthen movement programme.

This is very important and helps to decrease the stiffness in joints and muscles. It also increases the strength of the muscles, in order to improve physical fitness. This is necessary, to be able to return to activities such as cooking, housework, kneeling for prayers (Salah) and work.

Rehabilitation is for chronic pain. Chronic pain is a different type of pain. This type of pain affects the person for more than six months.

This pain can respond to treatments but often can persist despite trying different treatments. This is when rehabilitation can be helpful to find different ways to reduce disability and distress, and cope with life, with the pain.

Appendix 2

CENTRE FOR THE REHABILITATION OF THE PARALYSED (CRP)

Text taken from http://www.crp-bangladesh.org/aboutCRP_history.htm

History of CRP

The Centre for the Rehabilitation of the Paralysed, commonly known as CRP, was founded in 1979 by a small group of Bangladeshis and a British physiotherapist, Valerie Taylor. Miss Taylor came to the Bangladesh (then known as East Pakistan) in 1969 as a volunteer physiotherapist, and was appalled at the lack of facilities for the disabled and the often poor diagnosis by local doctors. The situation for the disabled was worsened in the aftermath of the 1971 Independence War, after which Bangladesh won its independence from Pakistan. After many years of disappointments and setbacks, CRP was opened in 1979. The premises were two cement storerooms in the grounds of a Dhaka hospital. The capacity soon grew from 4 patients to about 50.

CRP moved premises twice more before 1990 when land was purchased in Savar, and CRP's current headquarters were developed. From the original green-field site an extensive range of facilities has been developed to include world class treatment for spinal injuries, ground-breaking therapy services, an academic institute which is pioneering the teaching of new professions, workshops, an inclusive school and recreational facilities.

In addition to developing the impressive facilities in Savar, CRP has developed three further sub-centres, each with a different focus, in other areas of Bangladesh. The most recent of these is the exciting new centre in the Mirpur area of Dhaka. A further service location is planned in Manikgang, 30km from CRP-Savar.

Bangladesh Health Professions Institute (BHPI)

In addition to its work providing rehabilitation services for disabled people, CRP's academic institute, the Bangladesh Health Professions Institute (BHPI), has pioneered the training of relevant health professionals in Bangladesh. Courses are run up to BSc (Honours) degree level and affiliated with renowned institutions including Dhaka University and the Bangladesh State Medical Faculty. Some courses are the only ones

of their kind in the country. BHPI is a national resource of Bangladesh, without which the quality of health services throughout the country and the future of vital health professions would be seriously compromised.

Community Based Rehabilitation (CBR)

People throughout Bangladesh are touched by the work of CRP. Community Based Rehabilitation (CBR) projects operate in 13 districts of the country. Accident and disability prevention programmes include research components and aim to educate vulnerable groups on safe working and living practices. Advocacy and networking activities bring CRP's work to the attention of relevant officials and promote improved co-ordination among the many organisation with which CRP works. Awareness raising and publicity campaigns inform the population of relevant issues and attempt to break down the barriers, superstitions and stigmas which prevent disabled people from enjoying equal rights and opportunities.

CRP is the only organisation of its kind in Bangladesh, a country with a population of 140 million. The World Health Organisation (WHO) estimates that 10% of the population in Bangladesh are disabled.

Paediatric Unit

The main function of the Paediatric Unit is to run a two-week residential programme designed to integrate children with cerebral palsy into family and community life. To achieve this, children participate in physical and psychological therapy and carers/mothers are educated how to care for the child and made aware of disability issues and rights.

Children are referred to CRP for an initial assessment with a qualified therapist, either through other institutions or CRP's Community Based Rehabilitation programme. Depending on a child's condition, an appointment is then made for treatment and rehabilitation at CRP or to join the two-week residential programme.

After admission, the children are assessed in order to produce an individual treatment plan. According to the plan, the mothers/carers are taught physical movement and child management skills. Every morning there is group therapy, a hand function session and an individual session with a physiotherapist and an occupational therapist. Other components of the programme are health education, a disability awareness

programme and a group visit to the nearby National Martyrs Monument. After completion of the treatment period, a written home plan is devised and handed over to the families and a follow up appointment is made.

A recent and popular addition to resources available is the playground which includes typical playground equipment such as standing frames, slippery slide, hammock and a sandpit.

Appendix 3

CENTRE FOR DISABILITY IN DEVELOPMENT (CDD)

Text taken from <http://www.cdd.org.bd/>

The Centre for Disability in Development (CDD) is a non-governmental organisation in Bangladesh that works in partnership with existing development organisations to extend services to persons with disabilities.

Organisations are screened and selected as partners of CDD. CDD provides training to their staff members. CDD produces appropriate social communication tools and materials for raising awareness on disability issues. CDD is also building their capacities in various additional areas (sign supported Bangla, ICT for the visually impaired people, education...) to ensure that all disability groups will be included in mainstream development.

About CDD's Working Concept

CDD is working with the concept of Community Approaches to Handicap in Development (CAHD) that aims for equality of people with disabilities through integration of disability issues into mainstream development activities.

CAHD, and the processes necessary to implement it, are designed to be included into the ongoing activities of existing organizations and systems. Using existing organizations to establish CAHD is one of the core strategies in this concept.

For more information see

<http://www.healthlink.org.uk/projects/disability/articles02.html>

Community approaches - CAHD

There is increasing recognition of the value of actively involving people with disabilities in planning and implementing community-based rehabilitation programmes. At the same time, it has been recognised that disability issues and people living with disabilities need to be included in mainstream development programmes if these programmes are to have a real impact on reducing poverty.

In response to this need, the Centre for Disability in Development (CDD) in Bangladesh developed Community Approaches to Handicap (CAHD). CAHD is designed to help development organisations include disabled people in their activities.

CAHD starts with an organisation's current work and understanding of communities. Then, with small changes and with training of community development workers in the principles of CAHD, disabled people can be helped very quickly.

Rather than focusing on specific groups, the CAHD approach concentrates on all types of community groups, including those not normally included in development programmes, such as landowners and the middle classes. CAHD recognises that disability can affect anyone, and that, in order to bring about the changes needed by people living with disabilities, development programmes need to take a wider approach, looking at issues that affect other groups within the community.

CAHD is now being developed internationally with the support of Handicap International and Christoffel Blinden Mission. As well as the programmes in Bangladesh, there are pilot programmes in Nepal, India and the Philippines.

CAHD aims to raise awareness of:

- Disabled people's need for appropriate rehabilitation services
- The need to ensure the inclusion of disabled people in the planning, implementation and evaluation of development projects
- The importance of changing prevailing attitudes, such as ignorance, fear and prejudice, towards disabled people in their community
- The inability of a single organisation to meet all these aims; one of CAHD's core functions is to network with appropriate organisations to provide the skills that are needed.

CAHD in practice

Rehabilitation

Disabled people will not be included fully in their community unless basic rehabilitation is provided. This includes appropriate therapy and the use of supportive devices and equipment in order to prevent their impairment worsening and to ensure that they can be functional and mobile. The CAHD approach works to improve access

to referral services for specialist treatment as well as to develop links and transfer options between basic home therapy services and referral services at hospitals.

Changing attitudes

CAHD also works to challenge the attitudes of people and organisations. Negative attitudes can create barriers that result in the exclusion of disabled people from their communities.

Changing attitudes is a long-term commitment but research shows that people are willing to change their attitudes and practices when a change can be shown to be of advantage to themselves, their family and their community. By sharing information and experiences with disabled people through workshops and meetings, communities gain knowledge and understanding of disability and impairment and recognise the value of including disabled people in community life.

Inclusion

Disabled people have the same rights as non-disabled people to education, health care, employment and social activities. They also have a right to physical access to buildings in order to help them improve their quality of life. Once the attitudes of people and organisations change, disabled people will be able to play an active role in the social, economic and political life of the community. National and international organisations need to work with disabled people to advocate for legislation, policy and regulations for the recognition of the rights of the disabled person, as well as to seek practical solutions to address the difficulties of comprehensive inclusion.

Appendix 4

ADESH (ASSOCIATION OF DEVELOPMENT FOR ECONOMIC AND SOCIAL HELP)

About ADESH

Association of Development For Economic & Social Help (ADESH) was established in 16th December 1988, Victory day in Bangladesh. The initiators of the organisation attended a meeting at the Martyred Intellectuals Mausoleum at Mirpur, Dhaka district and discussed the social economic condition of the country. They found that a lot of work was needed in the development activities of Bangladesh. Then started different development programmes from 24th March 1989. ADESH registered with the Directorate of Social Services in 1991 to improve the socio-economic and health status of rural people. The Staff and volunteers are strongly committed to social work. They have been given training on development and social work from the Government and other NGO'S. Programmes include the following:

- Disability in Development
- Micro Credit
- Water & Sanitation Program

ADESH has addressed the socio economic problems of disabled people through its program to equalize their social rights. Through motivation, ADESH began the campaign to produce out a positive attitude in general people towards disabled people, their problems and our expected behavioural change with respect to the total phenomenon.

Social Afforestation program

ADESH introduce social afforestation program to protect the environment from ecological degradation.

Eye Camps

ADESH arranges eye camps for the poor and targets beneficiaries.

ADESH has worked heart and soul to play a complementary role in EPI coverage in the area in line with the Govt. objective of immunization of all the children. The Director of ADESH is a NGO representative of EPI program of Savar Pourashova committee.

Seminars & workshops

ADESH has organized a number of seminars & workshops on-

Environment & Afforestation

Gender discrimination

Legal aid and Micro Finance

Property eradication of distressed and exploited women: It is the vision of ADESH micro finance program to empower them in their socio-economic life.

Facilities to Members:

Those who repay their loan with regular instalment get back 2% interest. Remission of 100% profit in any projected accident. Service charge free loan for tube well and latrine installation.

- Distribution of # % (as per declared by the Govt) profit on saving money.
- (as per declared by the Govt) profit on saving money.

Strength of Adesh:

- Micro Credit and Account number is Computerized.
- 95 percent of staff are skilled in Micro Credit & other programs
- Cooperative Executive Board.
- Know all the people of the working area.

Adult Education:

ADESH organised a centre where poor people learn literacy knowledge.

Service Programme

ADESH introduced a needs-based program, namely a service program for the rural poor people.

Water & Sanitation

ADESH encourages to its group members and communities to used Tube-well water for drinking and domestic purpose. It also encourages the use of used water sealed latrine for defecation purpose.

Read more here: http://www.adeshbd.org/our_resources.html

MR. SUBRATO DEY

Founder & Executive Director

ADESH

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Appendix 5

REFLEXIVITY : RESEARCH ASSISTANT

The following information was provided by my Research Assistant Mr Md. Nouruddin ('Shanu') Choudhury in response to the two questions below which I asked him when the research was complete.

'In reply to your questions:'

What difference did you think it made if any to the research (to patients and then to the students of all varieties) that I was a *Bideshi*⁴?

'I believe and felt during the interviews that there was a great privilege of having you there during the interviews. They talked lot more than usual as they thought you had the power/ability to do something for them influencing job creations, respect and position at government level. So they talked about every single problem and concern they had. The other benefit was that you were able to ask different questions at different times which were not in the list of our usual questionnaire but was based on the response they provided. They found it really comfortable that you could talk in Bangla That made them comfortable responding in Bangla. Otherwise some of the interviewees would struggle to respond in English and we would have missed a lot of important issues as they would not be able to speak with a flow, especially the new students and the students that were not from CRP.

'Your presence was also very important interviewing the patients and relatives. Once again, the reason was that they felt that their voice were very important since a Bideshi was asking about their problems. Your speaking Bangla made them think that you knew about the culture and understood their problems and cared for them. They felt to speak about all their problem and they believed that you would have influence at some level to make their voice heard.'

⁴ Foreigner

How did you feel about the interviews yourself? - Do you think your own feelings affected anything or the way the interviews went e.g. that you were a PT, that you were male, that you were Bangladeshi, or that you perhaps had your own opinions about certain things we were asking about?

‘For the students, they knew that I was one of them. I went through the process of studying and I was the one in the practising field, so they believed in my struggling about the dignity, respect and unemployment problem. They knew that they might have to go through the same problems when they qualify. The interviewees outside were comparing their course design with mine and could talk about the lacks they had. They did respect you a lot as a PT, and they knew that you were from the ideal world of Physiotherapy and that it was really a good example in front of them to know how prestigious PT profession was worldwide and how it should be in Bangladesh. They also knew about your teaching role and they wanted somebody like you to teach them who was more qualified and would train them to become the best Physiotherapists.

‘Now, my presence in the interview was important because the students and other professionals e.g. CHDRP etc. knew that I was from their profession or similar. They could see their future in me; I was a representative for them. So, they believed in the purpose of the research and they believed that what they said were very important. Being a Bangladeshi removed a lot of cultural discomfort from them. They knew that they could trust us when talking about their problems or concerns. They expected that I understood their social and political problems.

‘My presence without you could have been a little bit difficult, particularly with the female participants as they could feel shy to talk and might not have talked about some of the issues. It was also possible that the boys would control the sessions and the girls would be left out. There were some points when I thought that being a Physio from CRP was a disadvantage as the people like CRTs e.g. Bilash, Munir etc. would not give us accurate information, but that was not what we found out. It was good that I was not employed by CRP at that time and that we were able to convince them that we wanted to know about their expectations and concerns about the profession they were in and not about what they thought of CRP and Momin. They knew that we were the media that could convey their demands to the higher level. They were not happy at their level of Status and title.

'As I mentioned before, Bangladeshis have lots of problems and they have a lot to say about them but they just don't have anyone to listen to them. We took our time to talk to them and that was very honouring for them. So, if there was any concern of disadvantage, that could be ruled out because we gained their faith in us they could talk to us about their problems and that we were willing to share each other's experiences. It was good that we were two moderating the sessions. Whenever you thought of an important point, you asked to clarify and I did the same too. Those questions were not in the list but they did bring out more insights.

'We both clarified our questions or modified them whenever we thought that they were not giving enough information or that they were not fully understanding our questions. I was involved in the data collection which was a great experience for me as it was a big area of research especially in Bangladesh context. I was learning and I wanted to hear. I was very concerned about the batteries though! Sometimes, we did extra interviews and we probably did not have enough batteries or enough cassettes. When the first years or second years talked, I could have felt like, "Good to have all those dreams. But pass the exam and come to the real field and then you will realise". Because I already completed their chapter and knew how the real world was.

'I do not think my own feelings had any negative effects on the interviews. My own views at times could have raised more questions and that was not a bad thing. That gave us more insights. We did try sticking to our usual questions but outside of that, we did ask them lots of sub-questions just to get more insights. Since, I was in the profession and was a qualified unemployed PT, I was able to throw examples to them ask questions. If I was not from the PT field, I could not set a good example to get close to them to ask about important concerns that were true in reality.'

Appendix 6

TOPIC GUIDES

Topic guide for users:

- History –their experiences around impairment
- Family responses to impairment
- Economic and social impact on family
- Community responses and attitudes experienced
- Beliefs around cause of impairment
- Other interventions sought
- History regarding gaining access to therapeutic source
- Perceptions and expectations around interventions
- Rights of disabled people
- Thoughts around the future
- Suggestions for change
- Content of interventions received
- Nature of relationship with healthcare workers
- Perceptions around attitudes of health workers
- Perceptions around efficacy of therapeutic intervention
- Participation in decision making
- Perceptions around the scope of practice of physiotherapists/related healthcare workers.
- Perceptions around society's provision for disabled people
- Local authority responsibilities

Topic guide for all interviews and focus groups

- Influences on initial decision to train
- Perceptions around role prior to training
- Anticipated role
- Scope of practice
- Perceptions around needs of patients/users
- Expected work locations
- Community / CBR interface
- Relationships with other practitioners
- Gender aspects of their role
- Adequacy of professional education/training
- Suggestions for changes in training/education
- Personal development needs
- Definitions of Professionalism
- Satisfaction with role
- Influences on socialisation
- Title/ Status once trained
- Educational aspirations
- Significant experiences

Appendix 7

GAIBANDHA-JAYPURHAT LEPROSY CARE PROJECT AND DANISHBANGLADESH LEPROSY MISSION (DBLM) HOSPITAL, NILPHAMARI

Bangladesh

Bangladesh is one of the world's poorest countries, and also the most densely populated. Leprosy is still a major public health problem in certain areas of Bangladesh. TLM works in Dhaka, Chandraghona, Chittagong, and in Gaibandha and Jaypurhat Districts.

Dhaka

TLM works alongside the Bangladeshi government and other NGOs in the slums of Dhaka, serving a population of 4 million through a leprosy control project. The project ensures women are given equal access to services.

Some of the activities covered include:

- **Weekly leprosy clinics for diagnosis and free treatment.**
- **Training seminars** to diagnose and treat leprosy for government health workers, and other NGO development workers
- **Prevention of Disability:** Through specialist physiotherapy at leprosy clinics, provision of protective footwear and self-care groups.
- **Community Health Education:** Ongoing education is vital to increase awareness of leprosy and encourage early treatment. Presentations are made to schools and factories and material distributed through community leaders.
- **Community-Based Rehabilitation(CBR):** Beneficiaries are trained in business skills, encouraged to form credit and savings groups and income generation activities started through loans.

TLM works with the children affected by leprosy in the slums of Dhaka, promoting basic education in mainstream schools.

TLM also works with local disability groups in Dhaka to keep leprosy on the agenda for NGOs, government services and church groups. TLM advocates for leprosy affected people to enjoy the same legal and human rights as everyone else.

Chittagong

TLM has worked in Chittagong District for the past 10 years supporting a network of leprosy clinics which provide Leprosy Control, Prevention of Disability and Rehabilitation activities. The project in the Chittagong Hills in South East Bangladesh serves to provide Community Health Education particularly in isolated tribal communities. Myths and misunderstandings about leprosy abound in this region, and health education is vital for clearing up the misconceptions.

The Chittagong Urban Leprosy programme works alongside the government health authorities and other NGOs to raise the profile of leprosy.

Gaibandha-Jaypurhat Leprosy Care Project

Groups and individuals are empowered through Community Based Rehabilitation.

As the socio-economic status and health improves, leprosy affected people can actively participate in their communities.

Danish Bangladesh Leprosy Mission (DBLM) Hospital, Nilphamari

This hospital serves as a major referral hospital in Bangladesh. Specialised leprosy services are provided, alongside reconstructive surgery and general disability care. DBLM also undertakes a leprosy control programme in the surrounding areas and an active Socio-Economic Rehabilitation project.

Many lives have been restored physically, psychologically and economically through DBLM's work.

Appendix 8

BANGLADESH PROTIBONDHI FOUNDATION

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What is the Bangladesh Protibondhi Foundation?

Bangladesh Protibondhi Foundation (BPF) was established in May 1984. Since its inception, the Foundation has been serving the intellectually disabled and cerebral palsied (brain damaged) children with much dedication and commitment. At present, the Foundation is serving the poor urban and rural disabled children from all over the country through its medical centres, special schools, sheltered workshops and Community Based Rehabilitation (CBR) Programmes. More than few thousand disabled children are being served by the Foundation. All our staff, teachers and therapist are well trained in their respective areas. In the medical clinic of the Foundation, the number of children in the waiting list is increasing every day. BPF runs the following programmes :

Shishu Bikash Clinic:

(Dhaka-2 clinics, Dhamrai-1 clinic) (Includes Medical Diagnosis, Psychological assessment and counselling).

Mother-Child Stimulation Programme

Dhaka – two programmes, one in each of the 6 CBR centres (Includes physiotherapy, speech therapy, occupational therapy for infants from birth to 4 years).

Distance Training Package Programme :

(Includes booklets for motor development, communication and speech development and cognitive development). Mothers come with their disabled child from all over the country who are served through training manuals known as Distance Training Packages).

Kalyani Special School for the Disabled : Dhaka

Two Special Schools. The special school was set up in 1984. Disabled children after screening and diagnosis are placed in different classes for training and education according to their age levels (special classes are named after Bangla flowers : (i) Komolkoli : age range from 4 to 8 years, (ii) Champakoli : age range from 9 to 12 years; (iii) Korobi : age range from 13 to 17 years and (iv) Madhobi : age range from 18 years and above.

Dishari (Special unit for the Cerebral Palsied)

Children age range from 5 to 14 years. This class caters for training and education of multiply handicapped children suffering from brain damage.

Karukor - Sheltered Workshop for the Disabled Adults

Students are employed in the workshop after graduating from school at age 18 and above, who are known as "workers". They are paid wages according to their training in different skills. The vocations offered are Craftwork, Carpentry, Clay work, Weaving, Sewing, Tie and Dye and Printing.

The Rural Multipurpose Project :

In Dhamrai, a rural branch of BPF and special school Kalyani comprise of a weekly clinic, mother-child stimulation programme, special classes, vocational training for the Disabled Adults and Distance Training Package Programme.

Community Based Rehabilitation (CBR) Programme :

At present BPF is running CBR programmes in the rural areas of Dhamrai, Savar, Kishoregonj, Narshingdi, Faridpur and Nabinagar, Comilla and one in Mirpur slum area. Disabled children in the rural and urban slums are first screened and diagnosed (through door-to-door visits) and then regularly served for training. All the CBR centres have started "Inclusive Schools" (school for all : normal, disabled and disadvantaged children).

Bangladesh Institute of Special Education (BISE)

This is a Teachers Training College affiliated with the National University of Bangladesh, which offers "Bachelor in Special Education" Degree (BS.Ed) for teachers

specialising to teach mentally retarded, visually impaired and hearing-impaired children.

Seminars, workshops, training, research and publication

BPF conducts scientific research in all aspects of disability (including international collaborative research) for keeping the professionals up-to-date as well as to improve the services to the disabled. Regular short and long training programmes, seminars and workshops are conducted for all level of workers - special teachers, therapists, staff and community workers from urban and rural areas. Research articles are published in local and international journals.

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