Ghosts and Germs: Cerebral Palsy in Nepal - A preliminary exploration of cosmology and disability

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INTRODUCTION

The need for cross-cultural studies of disability has often been stated but seldom acted upon. It was nearly thirty years ago that Edgerton, in a highly influential paper, made the intellectual case for increased study of disability within and between societies, both developing and developed (Edgerton 1970). His hope that such studies would soon be undertaken has not been borne out (Manion & Bersani 1987). This dearth of studies has not been just because of indifference: there are substantial methodological problems to overcome too, and even highly experienced researchers undertaking field studies for many years have raised questions about validity in studying disability in another culture (Miles 1992). Nevertheless, even studies with problematic methodologies or with limited exposure to another culture can enhance understanding if their findings are treated with caution and circumspection. More importantly, studies in other cultures can give insights into our own culture and can lead to questioning and development of taken-for-granted academic understandings.

The present study was conducted in this spirit: as a short-term, tentative exploration, envisaged as a feasibility study rather than a research project. It would be implausible to conceive of this study as a fully-fledged cross-cultural study, nonetheless it has provided insights and facilitated the formulation of tentative conceptual frameworks which can then be refined (or replaced) before being rigorously and empirically tested.

DISABILITY IN NEPAL

Nepal is an independent kingdom on the southern slopes of the Himalayas, situated between Tibet and India. It is predominantly rural (only nine per cent of the population live in towns or cities), has a population of around 23 million people and, although one of the poorest countries in the world, is undergoing

rapid economic development. It has an ethnically and culturally diverse population with a wide range of religious beliefs, including Hindu, Muslim, Buddhist and folk religions. It also has diverse medical and health-belief systems, including Sanskrit-based ayurvedic medicine, Tibetan medicine, homeopathy, acupuncture, unani (Greco-Arabic medicine), various types of spiritual healers (shamans, tantric Buddhist healers, exorcists, traditional midwives), as well as Western allopathic medicine (Durkin-Longley 1984, Streefland 1985).

While perceptions of illness in Nepal have received some ethnographic attention (McHugh 1993, Acharya 1994) there has been very limited research on either the prevalence of or cultural beliefs about disability. Where literature does exist, there are a large number of inconsistencies. For instance, the estimates of the proportion of disabled people in the total population of Nepal ranges from less than one percent, to three percent (His Majesty's Government 1993). Other small-scale studies estimate the prevalence to be as high as 13% (BPEP/DANIDA 1995, ICS/DANIDA 1995).

On the basis of data for other developing countries with similar demographic and socio-economic profiles to Nepal, there are estimated to be over 60,000 children in Nepal who have cerebral palsy. Furthermore (based on information from Professor Bhatuk Rajbandari, Director of the Nepal Cerebral Palsy Self-Help Group), it is estimated that less than a thousand of these children receive any type of biomedical therapeutic assistance, such as physiotherapy or speech or occupational therapy; and that less than 200 receive schooling, whether in "special" schools or in mainstream schools. Evidence from the Kathmandu Valley suggests that there are no reported cases of young people with cerebral palsy living past the age of twenty years. The situation in the rest of the Nepal is unlikely to be very different.

To date, there have been very few ethnographic studies of disability in Nepal and none specifically about cerebral palsy or similar conditions. On the basis of a year's fieldwork in 1976 and 1977 in rural settings near Kathmandu, Peters concluded that learning disabilities are recognised, labelled and stigmatised (Peters 1980). Richardson, during a two-month study tour of rural areas north and west of Kathmandu, estimated that around one per cent of the population had physical disabilities (Richardson 1983). Richardson's data collection methods were highly impressionistic and so his estimate needs to be treated with caution, but he made the interesting observation that high levels of physical impairment and disability were often coupled with low levels of handicap

(Richardson 1983).

Two other studies are relevant although they do not directly address issues of disability. Streefland, in an exploration of the interface between western and traditional medical systems, points out that ideas, beliefs and practices which are characteristic of a specific medical system are often deeply embedded within the culture of an ethnic or religious group (Streefland 1985). Pigg, after undertaking fieldwork from 1985 to 1988, concluded that modernisation and development have profoundly affected people's perception of medical realms and healing (Pigg 1995).

THE STUDY: AIMS & METHODOLOGY

The study aimed to explore the cultural beliefs and actions concerning cerebral palsy and similar conditions of: parents and families of children with cerebral palsy; medical, healing and other professionals working with the children; and, where possible, the children themselves.

Fieldwork was undertaken in Nepal between October and December 1997 by Rebecca Saul, who had previously undertaken two and a half years of applied and cultural anthropological fieldwork in Nepal. Data was collected in two locations: Kathmandu, the capital city (for four weeks: 30 interviews) and Janakpur, a medium-sized urban centre in South-east Nepal, just north of the border with India (for two weeks: 10 interviews).

In Kathmandu, the research population mainly comprised: staff, parents and children at the Self-help Group for Cerebral Palsy (hereafter SGCP) school and rehabilitation centre; families who were part of the outreach programme run by the SGCP; and staff of other organisations working in the disability sector. Several of the teachers at the SGCP school were themselves parents of children attending the school; field methodology included observing, interviewing and holding discussions with these mothers/teachers. The use of SGCP as a base permitted access to families from outside Kathmandu, when they brought their children to the rehabilitation centre for diagnosis, therapy or annual check-ups. There was also ample opportunity to have discussions with the Nepali staff at the centre. In addition to the school and rehabilitation centre, the SGCP runs an outreach programme to follow-up families who have visited the centre, and to establish new contacts with families who are referred to SGCP (by medical institutions and social services in Kathmandu, or by concerned neighbours and family members). These outreach visits enabled

Rebecca to revisit several of the families on her own after an initial introduction by the home visit staff.

In Janakpur, as in Kathmandu, the Janakpur school for disabled children was the main means by which contact was made with children with cerebral palsy and their families. The school is supported by funds from the local Hindu temple, although children of all faiths attend. The school is built on temple land and has three teachers, a carer/cook/housekeeper, and a gardener - who also brings disabled children to school on his bicycle. Between eight and fifteen children with various disabilities, including cerebral palsy, attend the school at any one time. As well as play and learning sessions, the children also make candles and chalk to sell in local bazaars in order to purchase equipment for the school.

Since the study was designed as an exploratory study, a central objective was to test our methodological approach. This included mobility mapping and ranking, ethno-histories and biographies of disability, art and story-telling, as well as participant observation, focus group discussions, unstructured and semi-structured interviews. We were particularly keen to develop ways of involving the children themselves in the research through conversational interviews and role playing.

In the course of the study, some important ethical issues arose from cultural and religious differences. For example, we learnt that one question which should never be put to adults who do not have a disabled child (e.g. some school teachers, physicians, carers, etc.) is: "How would you feel/cope if you had a disabled child?". The reason for this is the strong Hindu belief in self-fulfilling prophesies (see below).

THE FINDINGS

The principal findings which emerged from the study relate to: the rural-cosmopolitan continuum; the causes of childhood disability; local understanding about disability in terms of normality and deviance; and pluralism of beliefs. These are explored in turn.

RURAL-COSMOPOLITAN CONTINUUM

Nepal is an extremely heterogeneous society in terms of religion, demography and social geography, and is also in the throes of rapid, but uneven,

development. Thus it has a wide range of cultural beliefs and cosmologies. Based on our, as yet, tentative understandings of the cosmologies of different people and groups within Nepali society, we suggest that conceptualisations of disability can be placed on a continuum which ranges from "rural", through "urban", and on to "'cosmopolitan" (see Redfield 1947, Mahale 1983, Bell 1992 and Beggs, Haines & Hurlbert 1996). This is not an exclusively geographic model in the sense of rural dwellers having a rural ideology, and urban dwellers having an urban ideology (Streefland 1985). For example, there are a large number of people living in urban centres in Nepal who continue to adhere to a rural cosmology, and there are many Nepalis with cosmopolitan world-views who live in rural areas. Rather, it implies that the various ways in which people understand and deal with disability are influenced by their income, education, mobility, exposure to outside ideas and technologies, as well as other factors such as caste and ethnicity.

Broadly, a rural cosmology can be seen as one firmly based in traditional values, often strongly influenced by beliefs in ghosts, spirits and witchcraft. An urban cosmology will often be influenced by systematic belief systems based on the written word, often associated with Hindu, Muslim or Buddhist teachings and with ayurvedic medicine.[1] People with cosmopolitan cosmologies have been exposed to modernity in all its facets and will be informed about western biomedical teachings (such as germ theory) and will have a detailed awareness of: mother and child vaccinations; information about maternal nutrition; and therapies, such as physiotherapy, occupational therapy and speech therapy. They will also be aware of different types of medical services outside Nepal and the Indian sub-continent in places such as Hong Kong and Brunei, where the Brigade of Gurkhas had been based. (It should be remembered that Nepal is an independent sovereign state which has had a unique connection with Britain and the British armed forces through the Brigade of Gurkhas - which has Nepali and British officers and Nepali other ranks.)

In using this framework we do not assume that a cosmopolitan cosmology is the same as a "western" (biomedical) cosmology. It will generally be characterised by some degree of adherence to Hindu religious beliefs and practices, including ayurveda and astrology (indeed, cosmopolitans in Kathmandu often have strong beliefs in astrological influences). There are also other dimensions to understanding: some aspects of an individual's or family's beliefs may be embedded in traditional folk understandings, while others may have their origins in cosmopolitan experiences and encounters. Thus the boundaries between cosmologies are blurred and individuals often simultaneously hold several

different (and sometimes contradictory) beliefs from all three points on the rural-cosmopolitan continuum.

THE CAUSES OF CHILDHOOD DISABILITY

Perceptions about the causes of childhood disability vary greatly but there are a number of general and fairly widespread beliefs about pre-natal and post-natal causes. Pre-natal causes include:

1. parental sins in a previous life;

2. the child's sins in a previous life;

3. the results of accident, poor food, or unsuccessful attempts at abortion through the use of large amounts of medicine by the mother during pregnancy;

4. a "self-fulfilling prophesy" where thoughts about or visions of disability entered the mother's mind during pregnancy;

5. contamination through the mother coming into contact frequently or continuously with a disabled child during her pregnancy;

6. mother's ill health during pregnancy, which may or may not have supernatural causes; and

7. astrological mischance via an inauspicious alignment of stars and planets at the times when the child was conceived and born, as well as when the parents were conceived and born.

We can look at these perceived causes within the rural-cosmopolitan framework. Explanations one, two, and six (and, to a lesser degree, explanations four and five) are consistent with a rural cosmology: they find their meaning in often highly specific regional and cultural understandings. Explanations three, four, five, six and seven are in line with urban cosmology and can be seen as a composite of, perhaps even a transition between, rural and cosmopolitan cosmologies. Explanations three and six are cosmopolitan in orientation: they are grounded in biomedical understandings, as well as a more literate knowledge of Hindu teachings. To a lesser extent, cosmopolitans sometimes subscribe to explanation seven.

Post-natal causes include:

1. childhood illness;

2. possession or a curse; and

3. the child being contaminated or "infected" by contact with an already disabled child: "rok satné", literally: to trade or exchange disease - an explanation not uncommon among South Asians in England (Shah 1992).

Childhood illnesses are the most common explanation given by those who adhere to a cosmopolitan cosmology (explanation one). The rural folk explanation is more likely to be that the child or mother was possessed or cursed, or that the child was contaminated (explanations two and three). Childhood illness or contamination are more likely explanations for people with an urban cosmology (explanations one and three).

During the course of collecting disability biographies, parents mentioned all of the above explanations for their children's disability, as well as a few idiosyncratic or highly individual reasons. Sometimes both pre-natal and post-natal explanations are combined, as can be seen from the following examples:

> I was pregnant in the village and was ill for six months during the pregnancy. I did not eat much and maybe this was a cause. Also, my father-in-law give me joreebuthi [herbal medicine] and I think that it was bad for me. Rai mother, Kathmandu.[2]
>
> Our son was normal at birth and we did not see any abnormality until he was several months old. He became ill and was admitted to Kanti Hospital [in the Kathmandu Valley]. It was there that we believe he was switched for a disabled baby. Maybe, though, because our son was ill with pneumonia and was weak and defenceless he was attacked by a ghost in the hospital [this latter explanation is supported by the grandmother]. Brahmin mother and father, Bhaktapur, Kathmandu Valley.
>
> My son got encephalitis when he was two years old. That is why he has CP. There are no other explanations. Newar mother, Kathmandu.[3]
>
> This is the hand of God; it is God's will that Sunu has CP. Muslim uncle,

Janakpur.

UNDERSTANDING DISABILITY: DEVIANCE AND NORMALITY

The complexity in explanations of the causes of disability is mirrored - and even amplified - in relation to beliefs and understandings of its nature. As well as differences in cosmologies on the rural-cosmopolitan continuum, there are varying perceptions of different manifestations of disability. One key issue is that of "deviance" from the "norm". People may perceive some but not other disabilities as "normal" within their own society. An important element of this discourse concerns the categories of "non-normal" and "yes-disabled" suggested by Devereux (1963) and developed by Sachs (1995). "Non-normal" refers to deviance not yet categorised; "yes-disabled" refers to a specifically recognisable deviance which fits into an indigenous category. Devereux and Sachs conceptualise these statuses as mutually exclusive, but we found that this does not adequately reflect the range of rich and complex folk conceptualisations among Nepalis. In order to make a start it is necessary to create a new category which encompasses both the non-normal and yes-disabled categories (see Figure One).

Figure One: Non-Normal, Normal and Yes-Disabled

[The print shows a diagram linking the above categories.

The heading 'NON-NORMAL: deviancy not classified' is linked directly to the terms 'paagal', 'boksi lagyo' and 'upanga'.

The heading 'YES-DISABLED' has joint links: to the heading 'NON-NORMAL' and the terms 'laato/laati, 'mental retardation'; and to the heading 'NORMAL' and the terms 'hat kam negarné', 'kuta bigreko manché'.]

Non-normal: deviancy not classified

People who exhibit forms of bizarre behaviour such as extremely poor personal hygiene, lack of normal modesty and verbal ranting are often referred to as paagal - literally crazy. Alternatively, a person exhibiting similar behaviour but of a more disturbing or violent nature may be considered to be possessed by a witch: boksi lagyo. In these, as yet undetermined states, it is still possible that the deviation from normality may be temporary (see Stone (1986) for a discussion of indeterminate status in relation to a sudden onset of non-normal

behaviour classified as man bigrayo - literally broken mind).

Yes-disabled and non-normal

The category laato/laati in Nepal, meaning literally deaf and dumb males and females respectively, is often applied to people with a wide range and variety of disabilities, including communication difficulties (such as speech impediments) and learning disabilities. Laato/laati are generic terms covering specific permanent conditions which are seen as both disabling and deviating from normality in terms of either demeanour, behaviour or speech.

Yes-disabled but normal

People who, for example, have suffered from polio or who are crippled or have had limbs amputated, are placed in this category. Unlike the previous two categories of paagal and laato/laati, it is the disabilities (physical rather than mental), rather than the people, which are named and this is a reflection of their "yes-disabled but normal" status. People who have a crippled leg are described as kuta bigreko manché (man with a broken leg); if someone has a crippled arm, the disability will be described as hat kam negarné (arm which doesn't do work), etc. Even though their bodies do not meet normative standards, their behaviour, demeanour and speech fall within normative limits and they therefore retain their "normal" status.

These three examples are all consistent with rural Nepali cosmologies but there are other, different conceptualisations from the urban and cosmopolitan cosmologies (see Figure Two). For example, a cosmopolitan is unlikely to characterise a person as paagal or boksi lagyo. A cosmopolitan term for non normal behaviour presumed to be beyond the person's control is upanga - a catch-all term for an as-yet undiagnosed or unrecognisable condition that can be explained within a western biomedical framework.

Figure Two: Cultural Categories of Disability

	Rural	Urban	Cosmopolitan
Non-normal: deviancy not yet classified	Paagal (crazy) Boksi lagyo (witch-possessed)		Upanga (catch-all term for non-specified disability - with a western

		emphasis)
Non-normal and yes-disabled	Laato/laati ('deaf/dumb' - but generic meaning)	Specific to impairment: (often with biomedical label)
		Swasta mansthit "Mental retardation"
Yes-disabled but normal	Specific to impairment - descriptive of impairment (e.g. hat kam negarné, kuta bigreko manché)	Specific to impairment: often with biomedical label (e.g. CP)

Laato/laati are terms for non-normal and yes-disabled statuses which are commonly used within rural and urban cosmologies, and to a lesser extent by cosmopolitans. But cosmopolitans will use the term swasta mansthit (or its western equivalent "mental retardation") in situations where to western eyes a person unambiguously has severe learning disabilities, and this term is increasingly being used by urbanites too. The cosmopolitan yes-disabled but normal category is more straightforward in that a western biomedical term (or its shorthand version) would normally be used: e.g. cosmopolitans virtually universally refer to cerebral palsy as "CP".

People with learning disabilities, but no physical disabilities are normally referred to as "MR" - mentally retarded - by biomedical practitioners, and mental retardation is called swasta mansthit by other cosmopolitans. These diagnoses are sometimes added on to describe learning disabilities which accompany physical disabilities. Cerebral palsy is called mastiska pancha ghat (brain paralysis) by cosmopolitan lay persons, but is generally referred to as CP by educated urbanites and professionals who work with such children.

Perhaps specific terminology for different types of disability is not necessary for those with a rural cosmology, because it serves no purpose in terms of diagnosis, referral, treatment or therapy. There are no real options for biomedical treatment either in rural areas, or among those whose lack of education or money are effective barriers to accessing services if they do exist locally. Terminology becomes more specific as one moves progressively from rural to cosmopolitan, as it becomes more necessary to identify and gain access to specialised ayurvedic and biomedical health care resources.

Figure Three identifies those conditions classified in each of the normality/disability categories for each cosmology. All cosmologies treat the "non-normal: deviancy not yet classified" category in the same way. This category includes undiagnosed debilitating mental illness and socially unacceptable odd behaviour. In contrast, there are some subtle differences between the three cosmologies in relation to the "non-normal and yes-disabled" category: all cosmologies include learning disabilities, and these may be accompanied by physical disabilities, in this category; but treatment of communication difficulties varies. In a rural cosmology, communication disabilities are unequivocally situated within the "non-normal and yes-disabled" category, but this is not the case in a cosmopolitan cosmology (so long as there are no associated learning disabilities). The situation is less clear-cut in the urban cosmology where the extent of the communication difficulty and the presence of any associated physical disability are taken into consideration. A similar situation arises in the classification of the "'yes-disabled but normal" category, as evident in the final row in Figure Three.

Figure Three: Conditions Classified in Cultural Categories

	Rural	Urban	Cosmopolitan
Non-normal: deviancy not yet classified	Undiagnosed debilitating illness Mental illness Socially unacceptable odd behaviour		
Non-normal and yes-disabled	Learning or Communication difficulty: can be accompanied by physical disability	Learning difficulty: can be accompanied by physical disability; Physical disability along with communication difficulty	Down's Syndrome; Some cerebral palsy; Diagnosed learning difficulties: can be accompanied by physical disability
Yes-disabled but Normal	Physical disability with no learning disability or communication	Physical disability with no learning disability or communication	Physical disability with no learning disability; Some cerebral

	problems	problems; Mild communication disabilities	palsy; Communication disabilities

Other commentators have also noted the particular attention paid to communication difficulties in Nepal. They were explored in some detail in Peters' 1980 study. Peters undertook research among the Tamang, the largest ethnic group in Nepal, in two sites: a small market town and a village, both about eight kilometres from Kathmandu. He found that categorisation of people as laato/laati was "based partially on insufficiency of intelligence and behavioural adaptation, but primarily on speech incompetence" (Peters 1980, p. 352). Individuals with less severe speech impediments were called adha-laato/adha-laati (literally half-dumb, i.e. mildly yes-disabled and non-normal). He argues that competence in communications is important in the ritual life of the rural Tamang where clarity in enunciating mantras is essential in performing the rites necessary to fulfil the householder's role. Peters also stated that the Tamang believe laato/laati to be caused by "bad karma" (consequences of bad actions by parents or patrilineal kin in previous lives), in contrast with other mental disorders which were ascribed to supernatural causes such as witchcraft, spirit possession or soul loss and were therefore, in principle, amenable to cure by traditional ritualistic means (see also Stone (1988) for a discussion of indigenous Nepalese classifications of curable and non-curable conditions).

The placing of people within the three normality/disability classifications (illustrated in Figure Three) is a result of mediation between various actors. Most children with cerebral palsy go through several classificatory stages, beginning with either normal or non-normal, and ending up as either yes-disabled and non-normal, or yes-disabled but normal, depending on the socio-cultural, economic and educational characteristics of the child's family; the diagnosis; and the severity of the disability. There is no folk term for cerebral palsy in Nepal; children with undiagnosed cerebral palsy are either termed laato/laati, boksi lagyo or upanga depending on the biography and severity of the disability. The following case study illustrates this negotiation and the movement between conceptual categories of disability.

> We took Sunu to many hospitals and doctors in Nepal and India. Even after they told us in Patna [India] that he had CP, we continued to talk to western physios and doctors who visited Janakpur. Our friends and

> neighbours advised us that, with such cases, a hole should be dug and the child placed in it, with his arms resting outside the hole and supporting his body. They said that his body and legs would then straighten until his feet touched the bottom of the hole. This would cure him if it was done for one to three hours every day. The doctors told us to ignore this advice, which we did. Besides, we think that he has been attacked by a ghost. We paid much money to Hindu sadhus [ascetics] and Muslim holy men who said that they could cure Sunu, but they were just charlatans. Our neighbours and distant relatives sometimes ask us if Sunu is getting better, or if we have found a cure, but now we know he has CP so it will be very difficult for him to get better. We need to wait until the big western doctors find a powerful medicine to help Sunu. But he is getting weaker, worse, and maybe it will be too late for Sunu. Muslim grandfather, Janakpur.

While some community and family members (and also some traditional practitioners) believe that the boy has been attacked by a ghost (bhut) - a potentially curable, non-normal, condition - others believe instead that he is laato - an incurable, yes-disabled and non-normal, condition. The close family, based on a biomedical diagnosis, have accepted that Sunu has cerebral palsy, but are unsure of whether this yes-disabled condition is curable or not. Sachs writes: "among Turkish migrant families it seems that when someone is seen as non-normal, there is still the possibility of correcting this state into a normal state but when the person is classified as yes-disabled, it is a permanent state and there is nothing else to do" (Sachs 1995, p. 212). This, as the above case illustrates, is not always true in the Nepal context.

PLURALISM

Sunu's case study exemplifies the different beliefs that can be held simultaneously by different family members or even by the same person. Very little has been written about plurality of beliefs about the causes of disability, although Stone (1988) writes movingly of a family's pluralistic attempt to explain a teenage son's sudden severe mental disorder. There is, however, a considerable literature about plurality of beliefs and practices related to illness and healing in Nepal (Oswald 1983, Parker 1988, Subedi 1989, 1992).

Parents often access a number of different practitioners and healing systems in dealing with their disabled child. Anthropologists have described how traditional healers, unlike western-trained physicians, share conceptions of illness and

curing with their patients. Patients may consult traditional healers because they understand afflictions that biomedical practitioners deny are real, such as possession. Also, biomedical services can be geographically or financially inaccessible to patients, forcing them to rely on traditional healers when they might otherwise seek biomedical solutions. Finally, people may describe an illness-specific pattern of therapy to the outside investigator, but follow a multiple-use pattern (pluralistic) as they try anything that may provide relief (Durkin-Longley 1984). Parents often turn to a number of different practitioners in an attempt to make their child better.

Because many of the interview families were contacted through the biomedical system, family members were often reticent in discussing the alternative healing modes which they accessed. It was usually during a follow-up visit, unaccompanied by professionals, that people would reveal multiple-use patterns in dealing with their child's illness and/or disability. The following cases illustrate this:

> When Prasad became ill [at the age of two years] I despaired. I called every Buddhist, Hindu and Muslim holy man I could find. Some of them were very good, and could even tell me where my house was and what it looked like before they visited. I did this for two years, spending so much money, and going every day to Pashupatinath temple and other holy places to perform puja [religious offerings]. When Prasad was five I took him to the CP centre, and now I know that this was just his fate, and that no one is to blame, and that Prasad will never be cured [here she is crying]. Newar mother, Kathmandu.
>
> For many months after I noticed that Santi was ill I called a dami [traditional Hindu spirit-medium] to come and expel the evil spirits who had attacked her. But this did no good, so we took Santi to Brunei, where the medical doctors told us she had CP. Rai mother (her husband is an ex-Gurkha soldier).

CONCLUSIONS

This has been a small-scale exploratory study and any conclusions drawn from it need to be treated with caution. We make no claims that the families interviewed are representative of families of children with cerebral palsy in Nepal as a whole. Similarly we do not believe that the empirical findings have exhausted the possible - or even the most important - perceived causes or

cultural classifications of cerebral palsy in Nepal.

Any strength of an exploratory study such as this lies in its ability to illuminate an under-researched area and to encourage the development of concepts of more general significance. We believe that the rural-cosmopolitan continuum enables some of the complexities of pluralistic beliefs in developing countries to be unpacked. Even within an indigenous setting there are complex and sometimes contradictory relationships between different belief systems, as well as between the health care system and cultural values and beliefs within the community it serves. People can be reticent to discuss their beliefs concerning illness, disease and disability, and their own cultural categories and definitions, because they are not the same as the dominant medical perspective - or the perspective that the researcher is assumed to have.

We also hope that this paper has illustrated to those involved in both policy and practice the need to recognise that disabled categories and identities (as well as the causes behind them and the interventions sought for them) are culturally constructed. In one's own cultural context indigenous categories are, by definition, acceptable because they stem from the dominant cosmology and are widely held. The relationship between non-normal and yes-disabled sheds some light on the subtleties of labelling different statuses.

We believe that the conceptual frameworks that we developed to contextualise and to try to help explain our findings are of some heuristic value. While both frameworks need further conceptual refinement based on further research, it is our intention that they be a contribution to the oft-heralded but as yet nascent field of cross-cultural disability studies.

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END-NOTES

[1] Ayurvedic medicine has a complex and rigorous theoretical base and is rooted in the religious teachings and world view expressed in the Vedic scriptures of the Indian Sub-Continent.

[2] Rai is the name of an ethnic group indigenous to East Nepal. They have their own indigenous religious belief system, but nowadays generally adhere to Hinduism, especially if they live as an ethnic minority in areas of high Hindu concentration such as Kathmandu.

[3] The Newar are an ethnic group, centred in the Kathmandu Valley area, who adhere to both Hinduism and Buddhism.