

Leprosy in South India: The Paradox of Disablement as Enablement*

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Abstract: Rooted in ethnographic fieldwork with people affected by leprosy in India, this article argues that certain impairments, in certain social contexts, are simultaneously disabling *and* enabling. This paradox poses difficult challenges, not only for those working with individuals affected with leprosy, but for disability activists and policy-makers.

Key Words: social anthropology, leprosy, South India

Introduction

A clawed hand, with missing or deformed digits, and a face distorted by a sunken nose speaks unambiguously, in most parts of the world, of leprosy. It is the presence of these corporeal signifiers of untreated leprosy that, in the Indian context at least, stigmatises the person affected with leprosy as “a leper” and sees him, or her, barred from many social spaces. Prevent bodily difference, runs much contemporary thinking within leprosy aid agencies, and the person with leprosy will be able to continue with life as usual, rehabilitated within the community, rather than rejected from it. What such a perspective misses, however, is that the same clawed hand and distorted face that provokes social ostracism might also serve as a vital resource for collecting alms and for accessing other benefits. It is this paradox, and its ramifications, that this article sets out to address. It will argue that, in certain contexts, commonly accepted meanings attributed to disability, including those defined by the social model (Oliver, 1990), do not fit with the lived experiences of disabled people. This has important implications both for disability theory and activism.

My argument traces its roots to intensive field research conducted with leprosy-disabled people in South India, a group I have been involved with, in the blurred guises of social worker, friend, donor and anthropologist, for two full decades. Part of my recent fieldwork, in 1999 and 2000, was concerned with illuminating the embodied experience of leprosy. Accepting that leprosy was a socio-historically constituted category as well as a medical condition caused by *Micobacterium leprae*, I had set out to explore what it was like to have leprosy and, in some cases, to be labelled as a “leper.” This label, I should point out, was by no means an inevitable consequence of being diagnosed as having leprosy. Many contemporary patients on new drug regimens bear none of the impairments classically associated with leprosy and so do not usually become categorised as lepers. However, my focus here is on leprosy disabilities, by which I mean the social consequences of leprosy, rather than on leprosy *per se*.

Methodologically, in addition to a conventional anthropological toolbox of participant observation, surveys, interviews and life history accounts, I also experimented with participatory children’s workshops, informant diaries and drama performance. Contemporaneous notes were taken in a daily field diary format, and the illustrative data drawn upon in this article comes from that source. The majority of the research took place in one particular leprosy community, and my movements across its geographical boundaries – accompanying villagers on begging trips or on visits to natal places, for example – reflected those of the people with whom I worked. I did, however, also visit several other leprosy colonies and hospitals for short-term stays (from a

couple of days to a week), as well as the head offices of a number of leprosy aid agencies and the projects they supported.

One of the findings of my research was that the assumption of oppression or stigma I started out with formed far too narrow a framework within which to describe the daily lives of the people I worked with. Disability – or *vikalangamu* in Telugu, the language of my informants – was by no means peripheral to their experience, but it was nevertheless only one of the multiple identities on which people drew. In addition, there were times when aspects of the “leper” identity were as enabling as they were disabling. These aspects of disability are often absent from conventional analyses carried out within both medical and social frameworks. My suspicion that an ambiguous experience of disability is not confined to individuals with leprosy in a leprosy colony in India, however, has been borne out by other research. Bogdan’s (1988, p.1996) historical analysis of the American Freak Show, for example, reveals striking resonances between the relationships of showmen and those who have leprosy to their respective bodily differences.

Before illustrating how disability might be simultaneously disabling *and* enabling it is necessary to problematize the notion of disability and other terms associated with it. I thus begin here with a brief exegesis of the British social model, in response to which my argument has been formulated. Subsequent sections, offering an ethnographic overview of the community with which I did my research and an exploration of how leprosy has been socially constructed within India, provide the more specific contexts on which that argument draws for illustration. I then go on to offer particular examples from my own fieldwork and from a wider literature of how disabilities might, in certain cases, be construed as enabling. All this provides the background for our discussion, in a final section, of the implications of such findings for Disability Studies.

Definitions

Debate over the meaning of disability is not simply a matter of semantics. Definitions provide the conceptual frameworks through which disability is theorised and its experience interpreted. In Disability Studies the terms “impairment” and “disability” have been used most regularly in the ways the Union of the Physically Impaired Against Segregation (UPIAS), a British political organisation, defined them in 1976. These definitions are very familiar to disability scholars, but less so to social anthropologists. An “impairment”, according to UPIAS, refers to “the lack of part of or all of a limb, or having a defective limb or mechanism of the body” (UPIAS, 1976, pp. 3-4; cited in Barnes et al. 1990, p.28). “Disability”, by contrast, is defined as describing the social consequences of particular impairments. As Young neatly exemplifies: “Moving on wheels is a disadvantage only in a world full of stairs” (2002, p. xii)¹.

Such an approach has obvious and enduring appeal for disability activists. If disability is socially constructed, aspects of social structure can be identified as causing the barriers that prevent the full-inclusion of those whose bodies are different from a socially-defined ideal, rather than the biological realities of individual people’s bodily differences. Nevertheless, the imposition of a radical dichotomy between impairment as entirely biological and disability as entirely cultural is problematic in the same way that Cartesian dualism more generally has been shown to be². Quite apart from the bias toward physical disabilities in the UPIAS definition, it is also the case that “impairments” are culturally constructed in much the same way that “sex” is as culturally determined as “gender” (Moore 1994). The Tamasheq of northern Africa, for example, are said to consider the likes of excessive freckles, protruding navels and small buttocks as

impairments (Halantine and Berge, 1990, pp.58-59, cited in Ingstad and Whyte, 1995, p.6), none of which are likely to feature on a comparable list in, say, North America. On the other hand, Oliver's assertion that disablement is nothing to do with individual bodies (1996, p. 35), a statement which suggests that the social production of disability is entirely separate from the embodied experience of impairments, is also problematic. Such a definition demarcates disabled people exclusively as victimised objects without agency, a characterisation that this article aims to dispel.

As a way of confronting these problems with social model definitions, then, in this article I tend towards Shuttleworth's and Kasnitz's more recent definition of impairment as "a negatively construed, cultural perception of a bodily, cognitive, or behavioural anomaly" (2004, forthcoming). Disability, within this framework, is seen as "a negative social response to a perceived impairment" (ibid). In line with Shuttleworth's and Kasnitz's broad approach I would add that, since all bodily conditions are phenomenologically experienced, then impairment and disability should also be thought of as simultaneously embodied states.

I am particularly influenced in taking this approach by the work of Pierre Bourdieu, whose notion of "habitus" has the potential to cut through the head-on choice between models that privilege "agency" and those, like the British Social model, that privilege "social structure." In short, habitus refers to a socially constituted system of cognitive and motivating structures that provide both the individual and the group of which he, or she, is a part with a wide arc of predisposed ways of relating to, categorising, and responding to social situations (Bourdieu, 1990, p. 52ff). As the "embodiment of history" (ibid, p. 57), the habitus "makes possible the free production of all the thoughts, perceptions and actions inherent in the particular conditions of its production – and only those" (ibid, p. 55). Human action, then, is seen as being constituted through a mix of individually and collectively embodied constraints—which unconsciously limits the choices an individual may make—and freedom, within those constraints, to act.

Some have criticised Bourdieu's approach as too socially reductionist in the same way this article criticises the social model of disability (Shilling, 1993, p.146; Farnell, 1994, p. 931; Comaroff, 1985, p.5). I would argue, however, that Bourdieu's formulation allows for a more subtle interpretation. The habitus does not pre-determine a particular course of action in response to a particular stimulus; rather, it limits the range of choices and makes certain responses more probable than others. I suggest that the embodied experience of leprosy within a particular social milieu creates its own habitus; that is, its own ways of structuring responses to the world. The particularity of this experience has implications for how social responses to leprosy are responded to and embodied.

To make the case for a more nuanced, situated approach to defining disability, in the next section I provide an ethnographic description of the leprosy community from where I draw my main examples. I then offer a summary of the socio-historical factors significant in the construction of leprosy in India before coming to the central part of the article: an exploration of the ways in which a disability might also be enabling, and how we might account for this apparent paradox.

Bethany³

The community where I did fieldwork was a self-established leprosy colony in Andhra Pradesh, five miles inland from the Bay of Bengal on India's south-east coast, around 200 miles north of Chennai (Madras) and the same distance east of Hyderabad, the state capital. Since the

colonial phrase “leprosy colony” tends to conjure up the image of, in Goffman’s terms, a “total institution” (1961, p. 11), the words “village” or “community” probably offer more appropriate frames of reference. Bethany was neither a hospital nor a leprosarium but, at least in its early stages, a squatter settlement of patients with leprosy who had been discharged from a nearby mission hospital. Cured of their biomedical disease but either too institutionalised (many had spent up to a decade in the hospital) to return home, or unwelcome because of the stigma associated with leprosy, the early settlers built makeshift mud and thatch homes on railway owned wasteland, and eked out livelihoods from begging.

That was nearly half a century ago. In the intervening years the village has grown from an initial 30 inhabitants to a population bordering on 1,000. Around half of the population has had leprosy, the rest being their children and spouses. Of those directly affected by leprosy, 300 claimed to be disabled. Around 150 people still beg, but several social development programmes – started by various foreigners who came to stay in the village from the early 1980s – now provided work for around 300. There are also welfare programmes offering medical care, an elementary school, and food for those too elderly to work.

In 1999-2000 there were no other foreigners but myself in the village, and development projects were managed by a project co-ordinator appointed from within Bethany. However, much of Bethany’s income continued to be channelled through overseas donors, and a management committee on which they (as well as villagers) were represented, ensured a continued close relationship between Bethany and “the foreigner.”

The Social Construction of Leprosy

Leprosy, as a biomedical condition caused by the germ *Micobacterium leprae*, remains highly prevalent in India. 346,000 people, more than half of the world’s cases, were registered for leprosy treatment as of 1 April 2003⁴. The national prevalence rate was 3.2 cases per 10,000 people. To put these statistics into perspective, by the World Health Organisation’s (WHO’s) reckoning, leprosy will cease to be a public health issue when it reaches a prevalence rate of 1 per 10,000. Although this view is hotly contested by many leprosy organisations as over-optimistic, it is clear that India still has a long way to go.⁵

Nevertheless, leprosy is entirely curable with drug therapies, and many people affected by leprosy these days are successfully treated without any of the bodily changes traditionally associated with the disease. Indeed, Bethany’s early settlers had all been “cured” – in the sense that *micobacterium leprae* was no longer present in their bodies – and this was why the hospital saw fit to release them back into the community. The fact that most of those discharged from the hospital – many of them bearing the physical marks of leprosy – were unable to return to their natal homes suggests that leprosy is more than just a biomedical condition. Leprosy in India (and elsewhere), in common with other forms of disability, is also a socio-historically constructed category.

For the most part, constructions of leprosy are negative. Defining someone as a “leper” can legitimate their rejection because leprosy has long been perceived, literally in the case of classical Hindu law (Strange, 1859, p. 155), as the manifestation of wrong-doing on the corporeal body. Wise, a nineteenth century scholar of the classic Ayurvedic texts, notes that “when a person dies with it Hindus believe that the person will be affected with it in the next life, unless he performs *praschitta*, penance” (1845, p. 258). *The Laws of Manu* (Burnell and Hopkins, 1971, p. xxiv) also describe leprosy as a consequence of bad *karma* in a previous life.

Manu states: “[S]ome evil minded persons... for sins committed in this life, and some for bad actions in a preceding state, suffer a morbid change in their bodies.” They “bear the marks of their yet unexpiated crimes in the human form” so that “an atrocious sinner becomes leprous...” (Strange 1859, p. 155, cited in Buckingham, 1997, p. 60).

The *Kanmakantam* – a medical treatise attributed to the medical sage Agastyar (Kandaswamy Pillai, 1979, p. 256, 264) – makes a similar connection between leprosy and negative behaviour. The latter includes “plucking an unflowered bud; killing animals; causing trouble to one’s parents; destroying icons of gods; swearing at noble men; slashing down flowering plants in a bower” (Akattiyar, 1976, p. 16, cited in Buckingham 1997, p. 61). As a consequence, “coin-like scaly patches appear on the skin – they decay and blood drips from them. [To cure it] the *karmas* have to be expiated” (ibid).

Missionary discourses of the mid-late nineteenth century reinforced this by appropriating the leprosy-deformed body as a metaphor for the diseased soul.⁶ Biomedical practitioners, in positing segregation as a means of disease control, institutionalised the labelling of “the leper” and his or her removal from the family home. For a time, the fear that leprosy might be hereditary also permitted the segregation of male and female “lepers”. Mission hospitals created a parent-child type relationship between “lepers” and their mostly European carers; one which continues to shape the relationships people with leprosy have with foreign donors, volunteers and anthropologists in the present (cf Staples, 2005).

This morally negative construction of “the leper” as “a public nuisance” (Selections, 1896, p. 23) and as a potential source of disgrace to his or her relatives remains. Few people I spoke to in Bethany described leprosy in terms of *karma*, but, having converted in the Mission hospital to Christianity, some of them did describe leprosy as retribution for past sin. “I used to go with *so* many women,” one young man recalls being told by a more senior male, “Made *so* many mistakes in my life. But look at me now.” As he said this, the older man held out in demonstration what remained of his fingerless hands, and pointed down to the stumps of his feet. “I got all this as a punishment,” he said, “So you watch out!” The ill-treatment one received as a consequence of leprosy, so perceived, was the fault of the individual sufferer, not the social institutions that reproduced that ill-treatment.

Local people, for example, sometimes use the leper label to stigmatise their neighbours in Bethany as “drunkards” and “madmen”, and I have heard NGO workers refer to them (usually privately) as awkward, psychologically disturbed and (less privately) as “obstacles to development” (cf Gardner and Lewis, 1996, p. 15). The “leper” tag does more than identify a disease; in South India it also carries highly negative connotations about people labelled with it.

Represented in this way, the social model appears to have much to commend it as a frame for understanding experiences of leprosy-related disability. The case of a friend I have described elsewhere (Staples, 2003b, p.307) provides a neat example. Kotaiah asked a surgeon to cut his leprosy-deformed fingers off in a straight line, so it would appear they had been injured in a machinery accident rather than as a consequence of leprosy. The fingers were physically more useful as they were; he could still ride a bicycle, for example. As he saw it, however, they would be less socially debilitating if they were removed altogether. His disability, from this perspective, was entirely socially constructed.

However, Kotaiah was dissuaded from going ahead with the surgery, which suggests he came to recognise the practical value of leprosy-deformed fingers over having no fingers at all. What this begins to suggest, then, is that while disabilities are most certainly defined in the course of social interactions, they are not entirely explicable within a framework of oppression.

In the next section, I use ethnographic examples to show how people in Bethany, in developing a distinctively Bethany “habitus”, discovered a more explicit social value in the very bodily markings and deformities that simultaneously identified them as “lepers.”

Disability as Enabling

The Begging Tin as Passport

It is in the field of alms collection that my informants were most obviously enabled by leprosy disabilities vis-à-vis their neighbours in adjoining hamlets. The clawed hand, that stigmatised the leprosy affected person as “a leper” and saw him or her barred from many social spaces, was symbolically transformed in begging contexts to become a vital resource.

Begging in Bethany tended to be conducted a long way from home, most popularly on the streets of Mumbai/Bombay, where up to 150 Bethany dwellers spent large chunks of the year. Although group alms collection had once been popular, most of the begging people I worked with in 1999-2000 now preferred to work alone or in couples. “It’s safer that way,” one experienced beggar, Raju, put it. “If the police suddenly appear, a single man or woman can get away more easily than a big group. It also means that we get to keep whatever we raise, we don’t have to share it out with the rest of the group.” Nevertheless, although they spent their days walking through or, in the case of those without legs, sitting on the streets of the city, in the evenings they congregated together at the makeshift settlement they had created in the Mumbai suburbs. This settlement had been formed on encroached railway land and, as a consequence, was regularly disturbed by the municipal authorities with water jets. Even so, by employing their own watchman, at least they had somewhere to keep their essential belongings while they were out begging during the day, and a place to cook meals and sleep at night.

The begging itself also followed a routine, as this extract from the field notes I made while staying with the group in Mumbai made clear:

By 7.30am, we’ve arrived at [that day’s begging location] by train. We had taken tea at the station with a group of Bethany people – maybe 15 in total – and then travelled together. Only [my research assistant] and I have tickets. Raju [who is going begging] shakes his rattle and begging tin and declares “this is my season ticket, my passport!” When he comes out with us at other times, when he’s not begging, he always buys a ticket. The group congregates again on a street corner once they get off the train; they take tea and, once everyone is there, sit down on the pavement and pray together, the women covering their heads with their saris. Then they all set off, individually and in different directions, to work the streets of the surrounding area. Everyone has a rattle and a begging tin, the men have hats and the women all wear shirts over their saris and head scarves. In addition everyone carries a white shoulder bag made from sacking [which they] use to put alms in, especially gifts in kind (clothes, foodstuffs) and they keep a water glass and sometimes a bottle of water in there too.

As advised by Raju, while he goes down one street shaking his rattle and holding his can on his outstretched other arm (with bandaged hand), we take another route to [a nearby Catholic] church, where, he tells us, Bethany people will be working in shifts throughout the day...

...The first one we spot is Mariamma, going from car to car, asking the passengers for money – especially cars and taxis which are stopping to drop people off to go to church.

She's wearing the "Bethany uniform": plimsolls, socks and headscarf, and carrying a rattle and a tin...

...[Later], talking to Raju on the way to our lunch stop, he claims that if one in a hundred people gives he feels grateful. Usually they give 50 paise or a rupee coin – occasionally Rs5 or Rs10 if he gets them with a longer story, and people in cars tend to give more often than passers-by in the street. He demonstrates his patter: "Please sir, I am a leprosy patient. God bless you, and your family, and your children. Give me one donation, one rupee, 50 paise, sir." And if they ask (as he said they often did when we talked the day before) why he's not working? He replies: "My life is spoiled because I am a leprosy patient sir. What can I do?"

...I ask him about different begging techniques: he says that some people just stand (or sit) at the roadside; some go from car to car; some walk long routes, going into shops on the way and asking for donations; and that most people use a mixture of all these approaches.

Begging, as the above suggests and as my informants continuously stressed, was not a soft option: it was physically hard work and demanding on its practitioners' health. Leprosy deformities, however, meant that it was relatively lucrative. Those identified as "lepers" were broadly categorised in Indian society as "deserving poor" (Caplan, 1999, pp. 291-292). Their disease implicitly conferred upon them a right to ask that was not available to other people in India (cf Staples, 2003a). Fellow passengers on trains, popular begging locations, frequently told me they were willing to give to those whose impairments prevented them from working or who performed tasks, such as sweeping out the carriage, but resented being approached by others. A clawed hand or leonine facial features that unequivocally spoke of leprosy regularly induced a positive response from alms givers because, I would suggest, these features evoked both compassion and fear. On the one hand, people gave because they felt pity for these social outcasts with spoiled bodies who could not make a living, as they perceived it, in any other way. On the other hand, people gave because prompt payment removed the sight of the "leper", seen as a possible source of physical and moral contagion, as rapidly as possible. Raju's efforts to bandage his hand before attempting to beg were clearly not wasted. The suggestion of an impairment increased his chances of success, all the more so if that impairment became a physical metonym for leprosy as a socio-biological phenomenon.

The reality of givers' preference for those with the greatest deformities is borne out by comparing the monthly incomes of those who begged in Bombay/Mumbai. "I can make between Rs3000 to Rs4000 per month," Mariamma told me, "And that's without deformities, just a few patches, and by wearing old clothes. Sambaiah [who has no legs and gets about on a trolley], can make Rs450 per day. Those with deformed hands *and* legs can make even more." As a woman, Mariamma explained that she could make more money than an equivalent man, a statement with which others agreed. This was why many families sent their women rather than their men folk begging. The ratio of women to men at the Mumbai settlement when I spent time there was around 60:40. "A woman seems more vulnerable," Rama Rao – the husband of a woman who went begging while he worked in Bethany – told me when I asked him why he thought this was. "And people think she doesn't have as many opportunities as a man if she becomes destitute." In short, there was a direct relationship between the level of disability (and being a woman was relatively disabling) and income that could be achieved from begging. In any case, monthly

income was significantly more than that which could be made from working in NGO-sponsored income generation projects.

In terms of attracting money from donors, too, leprosy had an appeal beyond that provided by poverty or “neediness” alone. Many of the small hamlets that surrounded the leprosy community where I did fieldwork were at least as poor and in many cases poorer than Bethany, and yet none of them attracted the interest from overseas and local donors that the leprosy colony did. “No-one has to go hungry here,” my friend Rama Rao once told me during a general conversation about the difficulties faced by Bethany villagers. “They do sometimes in [the next village] though: they go out and do labouring work in the fields and with the money they make that day they buy rice. If they don’t work they don’t eat. Here nearly every family has some stock of rice in the house, even if we have to eat it just with pickles sometimes.” The rationale for being owed more by society than their healthy counterparts in other villages was that, because of the ostracism and geographical dislocation they had endured as a consequence of leprosy, compensation was owed to them as a right.

It was also significant that the leper identity provided opportunities to other stakeholders. For colonial missionaries (and now indigenous evangelists), “the leper” was not only a site for salvation but a potential evangelist who could preach “the two-fold gospel of spiritual and physical healing” (Cochrane, 1927, p. 22). For Government organisations, NGOs and their employees, the “leper”, redefined in the present as a “client”, offers both a site for rehabilitation and jobs for leprosy workers.⁷ In recognising the opportunities they represented to other groups, my informants were able to negotiate social and economic advantages and to create new identities, beyond those achievable to other categories of rural poor, that offered dignity and self-respect. The fact that they recognised the commercial potential of their bodily condition was evident in Bethany from the recently erected signs prohibiting photography, designed to prevent images of them being used by NGOs for purposes that would not profit them directly (cf Staples, 2003b, p. 310).

In terms of direct benefits to those whose bodies communicated leprosy, the missionary construction of the “leper” has permitted an ongoing special relationship with “the foreigner” that has been economically beneficial. The relationship also enabled my informants to deflect responsibility for their welfare onto what they constructed as an overseas, wealthy Christian “other”, who had a duty to help them. Church-links within India also provided “lepers” social capital with which to renegotiate identities as Christians.

Those with physical deformities that communicated the leper identity could also play on local fears of their apparently rotting leprous and, by association, corrupting bodies, both to reinforce the effectiveness of their street-begging and to make powerful protests to the authorities. The offer of people deformed by leprosy to stage a sit-in at the police department to help my visa-extension application on a previous trip to Bethany is an extreme example of this. More subtly, appeals for rations, pensions and other Government grants were regularly strengthened by exposing body parts that could simultaneously evoke both fear and compassion at meetings with officials.

In individual cases, too, leprosy had been life transforming in positive as well as negative ways. Esther, for example, was not alone among the older generation of women when she described leprosy as “a blessing,” claiming it was through the disease that she had come to know the “true God.” More tangibly, Venkateswarlu had become more powerful than he otherwise would have done specifically because of his disease and the impairments with which it has left

him. I offer the following case study, pieced together from a series of interviews Venkateswarlu gave me, by way of illustration.

Venkateswarlu's Story

Venkateswarlu was the youngest son of a family of silversmiths who lived and worked in a large town less than 100 miles from Bethany. The stories he told me were self-consciously framed by a wider narrative of suffering, caused both by the physical effects of leprosy, and by the stigmatising and excluding actions of other people. Interview situations also provided an opportunity for him to make the case for leprosy affected people to be awarded compensation from Government and NGOs for that suffering. Despite offering a largely negative picture of his situation, however, a counter-narrative that ran through much of Venkateswarlu's life history account was of successful campaigning and power gained not in spite of his leprosy but because of it.

Venkateswarlu became a resident in the mission hospital next door to Bethany in the 1950s as a result, he says, of being stigmatised by his sister-in-law, who would not allow him to eat from the same plates as the rest of the family. Outward changes to his physical body did not occur until the 1970s. In the course of that decade he lost his nose, most of his fingers and his toes. In the early 1980s his eyesight also began to deteriorate. Although the drug therapy that became available at around that time prevented further deformities, Venkateswarlu was already physically unable to work, and spent much of that period begging. More recently, he has received support from one of the community's welfare programmes, which provides him with a small monthly allowance and basic provisions.

Venkateswarlu has also been a vocal force in community politics, with few people willing to cross him openly. He had been elected four times as President of the Colony's Elders, and in-between times had been involved from the peripheries, advising newer Elders on procedures, chairing community meetings and contributing to marriage negotiations. As a visibly leprosy affected man, Venkateswarlu was also the main speaker every year at a local rally and meeting to mark anti-leprosy day, an occasion he used to make the same case for compensation that dominated the accounts he gave me. More recently, he had also become the President of a state-wide leprosy association, which aimed to join with similar associations in other states to lobby Government at the centre.

"In Andhra Pradesh," he told me, "There are 73 colonies, 20 are getting something from the missionaries or from other foreigners, but the rest are begging. Before the State Government used to pay us Rs.30 per month per person – Rs1 per day – and at that time we made contact with the other colonies, and elected a group of seven members, like a committee, to fight against the Government for more money. We wanted Rs300, at least. Also I spoke in some major cities, trying to get across to the public that we have come from families just like theirs: that we need help. For example, the Government could give some land and housing for patients... Now, [the pension] used to be Rs30, now it's Rs75 per person. I went to the Assembly in Hyderabad and I spoke to N T Rama Rao [the then chief minister] and sent letters to the Central and State Governments. Now they get Rs75."⁸

Venkateswarlu's role in bringing about the increase in State support for leprosy-affected people was by no means uncontested, but the claim had nevertheless brought him some kudos in the village. His membership of the state-wide association was also, some villagers claimed, a

way of attempting to become one of the President of India's appointees to the Rajya Sabha (Indian parliament's upper house) where he could wield national influence.

The latter campaign was unsuccessful, indicating the limits of Venkateswarlu's authority and influence beyond the perimeters of the leprosy colony. Nevertheless, his story illustrates how, in certain situations and from his own perspective, an institutionally recognised disability can become empowering as well as excluding. To frame it as a question: had Venkateswarlu not had leprosy and remained a part of his family's business in his natal home, would he have achieved the same level of political authority? It is impossible to predict the trajectory his life might have followed had he not been stigmatised by leprosy (and Venkateswarlu was not prepared to speculate), but I would suggest that through his inclusion as a member of a nationwide group of leprosy affected people he had become more feared, respected and listened to (all qualities he found desirable) than he otherwise would have done. This was not about making the best of a difficult situation by responding to it positively or by over-compensating for a loss: it was about gaining advantage precisely because of his situation. If the phenomenon of embodied advantage through physical markings otherwise considered disabling was a particular feature of leprosy, this would in itself be interesting. As I shall show in the next section, however, there is evidence to suggest other forms of negatively construed bodily difference also enable in various ways.

Bogdan's Freaks

It was in reading Robert Bogdan's historical accounts of the American Freak Show that I initially became struck by the similarities between the situations he described and those I encountered in Bethany. I thus use Bogdan's work here as an illustration of the ambiguous ways in which human difference might be experienced, before turning, towards the end of the section, to consider a wider literature that suggests enabling aspects of disability might be widespread.

A stress on exclusion, stigma and devaluation has dominated much of the debate in Disability Studies, and while Bogdan recognises the importance of these factors his account focuses more heavily on the ways in which the American Freak Show gave value to human difference. "Some were exploited it is true," he admits, "But in the culture of the amusement world most human oddities were accepted as showmen" (1988, p.268). Advocating a sociology of acceptance to counter the emphasis on social exclusion, Bogdan's layering of life history accounts demonstrates that, in the early part of the twentieth century, abnormality, like the clawed hand of untreated leprosy, was often a "meal ticket" as much as a handicap (1988, p.277). Subsequently, descriptions of human variation have become increasingly pathological, with different bodies medically reclassified as dysfunctional rather than as curiosities. As a result the Freak Show has become ever more marginalised. One of Bogdan's case studies, taking us as it does to the core of contemporary debates over disability theory, is worth retelling here.

Otis "The Frog Man" Jordan, was a black man from Georgia, his nickname, presumably, a reference to his unusually formed limbs. His act, Bogdan recalls, was to roll, light and smoke a cigarette using only his lips. Until he was 28, he had eked a living from hawking pencils and other goods; his break came when he showed his cigarette trick to a carnival that was passing through town and was asked to join up as a novelty act. He took up the offer, describing it as "the best thing that had ever happened" (1988, p. 280). In addition to enjoying the travelling and being accepted as a valued member the group, the income had allowed him to buy a small house in his hometown. Having improved his life through participation in the carnival, Jordan now

raised strong objections to the lobbying by disability activists to ban the Freak Show on the basis that it is degrading to disabled people (ibid, p. 281).

In considering the extent to which Jordan's bodily difference was enabling rather than disabling, similar questions to those I asked in relation to Venkateswarlu's case might be posed. What would his situation have been like without the bodily difference? Could he have made a good living? Bogdan's evidence suggests Jordan's options as a poor black man would probably have been just as limited and would almost certainly not have included anything as lucrative as joining the carnival. Jordan's differences, in common with the other variations described in Bogdan's book, were valued, both by the showmen themselves and the wider society. They also brought benefits that, from the performers' perspective, exceeded the disabling effects of the difference.

This is not, I should stress, to be an apologist for the kinds of negative representations opposed by those who called for a banning of the Freak Show. What the difference of position between the two groups illustrates very pertinently is the tension between the interests of the individual and the interests of a wider community of disabled people. While Jordan felt his right to make a living in the way he chose was under threat, activists saw the exoticised representations of disabled people that were promoted by the Freak Show as damaging to disabled people in general. A similar tension exists between leprosy aid organisations and individual leprosy-affected people. The former aim to restore the dignity of leprosy affected people by de-linking associations between the condition and begging. For the latter, begging is often a route to dignity through the accumulation of material wealth (Staples, 2004).

Watson (2002, p. 524) highlights a parallel tension between the British disabled people he interviewed, among whom there was little support for an identity politics based on the notion of a common group identity of disabled people, and the social model activists who argue for precisely that. For the activists, disability is conceptualised as a shared experience based on common interests (e.g. Barnes, 1990; Campbell and Oliver, 1996; Finkelstein 1993; Shakespeare, 1996). Kurzman's observation from fieldwork with amputees that there is often a "hierarchicalization of disability" (2003a, p.2) suggests further problems with the social model approach. I turn to this, and other issues this inquiry has opened up, in the concluding section.

Discussion

This article has considered contexts in which disability might be simultaneously enabling and the issues that an investigation of those contexts reveals, particularly concerning the ways in which disability is defined and used. With reference to the latter, my aims have been two-fold. Firstly, I wanted to highlight the problems inherent in a universal social model – in the singular – of disability. Secondly, I wanted to illustrate how theory induced through detailed ethnographic fieldwork might provide more workable alternatives.

Before I come to these, however, there are some important caveats to the case I have been making. Firstly, identification of enabling aspects within a disabling situation needs to be distanced from overly positive accounts, coloured by what Abu-Lughod has called "the romance of resistance" (1990, p. 41). Could I, in emphasising the potentially enabling effects of what are otherwise described as disabilities, be accused of highlighting "weapons of the weak" (Scott 1985; 1990) at the expense of the "tools of oppression?" Certainly, I have made use of Scott's framework in the past as a way of reconceptualising the experience of leprosy-affected people from perspectives that go beyond narratives of stigma and oppression (Staples 2003a; 2003b;

2005). Here, however, I have been less concerned with resistance *per se*, than with the ways in which people might strategically maximise embodied advantages. These advantages need to be taken into account to provide more nuanced analyses of disability, within which people are not required to be *either* disabled *or* able-bodied. In short, my argument that disabilities can be enabling should not distract from the reality that they simultaneously, and by definition, also create disadvantages.

This brings me to a second caveat. In recognising the ways in which negatively perceived bodily differences might be positively utilised I want to avoid any suggestion that social processes of disablement can be justified. On the contrary, my argument is that attempts to overcome discrimination in general are compromised when the specific situations of people who have been disabled in particular ways are glossed with over-arching theory. “The job of those who want to serve people known as disabled,” as Bogdan puts it, “Should be to get behind the scenes, to know them as they are, not as they are presented” (1988, p. 279). The extent to which anyone is knowable beyond their multiple representations is, of course, debatable. Nevertheless, it is in uncovering more nuanced representations, based on observation of everyday life, that the social or cultural anthropologist can make the most significant contribution to the interdisciplinary arena of Disability Studies.

What has also emerged through this inquiry is the need for more nuanced theory. Social model definitions of disability are problematic because they are predicated on an assumption of biological abnormality – on “impairments” – that simultaneously undermines the notion on which the theory is centred: that disability is entirely socially constructed. These criticisms of the social model have been well-rehearsed elsewhere (see, for example, Tremain, 2002, pp. 33ff) and continue to dominate much of the traffic on an e-mail list dedicated to discussion of the social model.⁹ Here, I limit my critique to the following points.

Firstly, a theoretical model that denies the direct relevance of embodiment to a definition of disability renders the term all encompassing in terms of *who* might be included, taking in lesbians and gay men, black people and women, for example. At the same time, it renders the term too narrow in terms of *how* it categorises these people once labelled. While there is some merit in an inclusive approach, inasmuch as other socially oppressed people might have experiences in common, the notion that virtually all of us are disabled reduces the potency of “disability” as an identifying category for the purposes of activism. More significantly, in imposing (or in taking on) an identity that assumes oppression, those who are disabled are denied agency and are categorised by what they cannot do or are prevented from doing, rather than by what they can do. This identity often becomes seen as separate from and more important than other personal identifying factors, such as gender, ethnicity, religion, class or caste, with which a disabled identity inevitably mingles. My informants were not just “lepers”; they also identified themselves as Christians in relation to local Hindus; they were located within networks of familial relationships; and they had identities related to their relative status within the leprosy community. In addition, as my ethnographic examples have illustrated, bodily differences are actually much more flexible to interpretation and relative to the broader circumstances in which they are located at particular times than a model that reduces disability to oppression will allow. While leprosy is certainly disabling in India, that is not to deny that its marks might also be socially enabling in particular contexts.

This brings me back to the central paradox of how that which is defined as disabling can also be enabling. The answer, as I have shown, is that this is not paradoxical at all. Rather, the ways we have used the terms have served to straitjacket our thinking. Disability, in the senses

that it has been defined both medically and by the British social model, is too generalising a term. For one thing, it is inadequate to differentiate between states of being that might demarcate one as different and evoke particular responses from others. For another, it falsely limits the perspectives from which we are encouraged to examine the experiences of a person so labelled. Kurzman's informants, for example, did not consider themselves disabled, but—as a chapter title in his Ph.D. dissertation summarises it—as “able-bodied if not total-bodied” (2003b).

One way of extending thinking beyond this either/or choice between disabled and abled is to utilise more fully in Disability Studies Bourdieu's idea of “habitus” (1977; 1990), as outlined in the introduction to this article. Such a formulation allows for the possibility that aspects of a disability might offer advantages, without insisting that those who gain from those advantages are necessarily conscious of manipulating them. Social constructions of leprosy, for example, are embodied in the habituated action of proffering an out-stretched, fingerless hand to solicit alms in the course of a typical begging transaction.

An additional, and wider, solution, within which Bourdieu's analysis should play a useful part, lies in abandoning a grand theory approach to disability altogether, instead using detailed ethnographic research into particular cases to induce or suggest suitable theoretical approaches for particular contexts. Such an approach is not only more theoretically satisfying, it is also important from a policy perspective. Existing interventions have tended to follow two routes. On the one hand they focus changing or adapting the disabled person's body, using anything from prostheses to plastic surgery to electric shock treatment, to enable the person to fit into existing society. On the other hand, more enlightened approaches aim to address social attitudes towards disability and to promote a more universally accessible environment. Both routes generally fail to incorporate the positive aspects of an otherwise disabling situation that might disappear when well-meaning interventions change those situations. Leprosy affected people without bodily marks, for example, make less money from begging, while Otis “The Frog Man” Jordan and his fellow showmen faced losing their livelihoods because of changing attitudes towards the Freak Show.

My suggestion is not that individual or small group perspectives are always prioritised over those of the wider society. Rather, it is that policy makers centrally incorporate ethnographic particularities into building solutions. Plans for the eradication of leprosy as a biomedical condition, for example, need to include genuinely viable alternatives to begging, identified by leprosy-affected people themselves, which replace not only the higher earnings but the freedoms and self-respect achieved through begging. They also need to include a social space for those already disabled by leprosy, like the people I worked with in Bethany, for whom eradication is an irrelevance. More ethnography, in India and elsewhere, points the way to going beyond ethnocentric analyses based on a narrowly defined dichotomy between impairment and disability.

*An earlier version of this article was presented at the Western Social Sciences Association (WSSA) Annual Conference 2004 in Salt Lake City, Utah, an event I attended with generous support from the British Academy and the School of Oriental and African Studies, University of London. I am grateful to Gary Linn and other contributors to the conference for their comments. The fieldwork on which the article draws was funded by the UK's Economic and Social Research Council (Grant R00429924418), as was the post-doctoral fellowship during which it was written (Grant PTA-026-27-0342).

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Endnotes

¹ For a more detailed outline of the social model that developed out of the UPIAS definitions – still the dominant paradigm in interdisciplinary studies of disability – see Oliver (1990) and Barnes, Mercer & Shakespeare (1999).

² For a more detailed critique of Cartesian dualism as universally applicable, see, for example, Marriott (1989), Busby (1997) and Staples (2003b).

³ I have provided far more detailed descriptions of this community and its development – under the pseudonym Anandapuram – elsewhere (Staples, 2003a & b; 2004 & 2005).

⁴ All statistics quoted in this paragraph are from the World Health Organisation's site. Retrieved March 26, 2004, from www.whoindia.org/leprosy/02-epidemiology.htm.

⁵ A Congress of International Leprosy Associations, held in Paris in 2002, concluded there was no evidence leprosy will die out at a predefined level of prevalence rate, and the statistics painted an overly rosy picture by including Western countries where the prevalence rate is virtually zero. See the webpage <<http://www.lepra.org.uk/review/june02/supplement/contents.html>> to download a full copy of the Congress's report, also published in *Leprosy Review* 2002, 73, S3-S62. The Congress took place 25-28 February 2002 in Paris, France. See also Staples (2004) for further debate around the official discourses on leprosy eradication and management.

⁶ See, for examples of how leprosy was portrayed in a comparable way in European medieval literature, Skinsnes and Elvove, 1970; Brody, 1974; and Stephen, 1986.

⁷ The International Federation of Leprosy Associations' (ILEP's) guidelines for socio-economic rehabilitation prefer the term 'client' to the many others applied to those who have or have had leprosy (see, for example, Gopal, 1999; Nicholls, et al. 1999).

⁸ As of January 2000, when the interview took place.

⁹ See the jisc-mail list "Disability-Research" online via <www.jiscmail.ac.uk>.