Stigma, Contagion, Defect: Issues in the Anthropology of Public Health

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The concept of stigma gained currency in social science research first through the work of Erving Goffman[1][1]. Much of this research has been framed by his interests in questions of micro-social processes within which the self is created and maintained. Goffman applied the term (negative) stigma to any condition, attribute, trait, or behavior that symbolically marked off the bearer as "culturally unacceptable" or inferior, with consequent feelings of shame, guilt and disgrace. He distinguished between three types of stigma associated with abomination of the body, blemish of individual character, and with membership of a despised social group. The common element among these three types was the notion of a spoilt identity and its management through stances such as concealment, defiance or irony. In considering this concept and its relevance for issues in public health, I shall ask whether we need to place this concept within a family of concepts – e.g. that of contagion, defect, and disability, in order to give it a greater cross-cultural relevance. Stigma manifests itself most clearly in what is at stake in face-to-face relations – yet the programs and policies of larger social actors such as the state and global institutions are implicated in both, the production and amelioration of this condition. Let me start with the way that notions of stigma come to be linked with other related concepts such as that of contagion and defect within what Arthur Kleinman calls local moral worlds, and in the policies and programs of larger social actors[2][2].

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[1][1] Erving Goffman, *Stigma: Notes on the management of spoilt identity*. Englewood cliffs, N.J.: Prentice Hall, 1963.

[2][2] Kleinman's notion of `local moral worlds' is complex but it essentially signals the importance of how we come to invest in relations. Thus traditions and customs are neither a matter of following pure habits, nor indeed of constant self-interrogation about how we make meaning of culture. Rather it is Kleinman's thought that the making of moral beings depends upon the way we place ourselves within local worlds and relationships. Local then does not have an exclusively spatial reference – it relates rather to quality of relationships. Kleinman also speaks of the tension between the *moral*, shaped in local worlds and the *ethical* as allegiance to abstract principles. As I understand him, ethical principles become grounded only when they become entangled in the discourse of local worlds. See Arthur Kleinman, "Moral experience and ethical reflection: Can ethnography reconcile them? A quandary for the "The New Bioethics" Daedalus, 1999, 128 (4): 69-99. I see this complex engagement with the moral in Kleinman's work as related to Wittgenstein's basic insight about *rules* as always entangled in *customs* and *habits*. See Veena Das, "Wittgenstein and anthropology", *Ann. Rev. Anthrop*., 1998, 27:17 –95.

Stigmatized subjects and the connections between body-selves

Although Goffman was sensitive to the differences between the three types of stigma that he identified, the unifying concept of a "spoilt identity" and its management, loaded his analysis towards a highly individualistic rendering of the subject – the individual appears in his analysis as the sole bearer of value. Since agency is conceived in the form of resistance to collective representations, the concept of culture comes to rest on the notion of *shared values and representations* with rather less attention to the nuances through which culture is in fact embodied or actualized in individual lives. This leads to a neglect of forms of collective action on the one hand, and of contests over values within the rubric of everyday life, on the other. Elsewhere I have argued that whereas the language of normality assumes a sharp *hiatus* between norm and its transgression, we can find a hyphenated relation between these in the blurred contours of everyday life[3][3]. I suggested further that the notion of domestic citizenship may be useful to capture this nuanced relation of norm and transgression and to see how families may mediate between the collective level of social response to conditions of stigmatized disability and the individual life trajectories[4][4]. Recent ethnography offers interesting examples of how the immediate community within which the domestic is embedded (be it kinship or neighborhood) becomes the world within which family often has to confront the opprobrium of stigma, making it difficult to postulate a seamless continuity between family and kinship or community in the case of stigmatizing illness. This, in turn, yields startling revelations about stigma associated with disease, disability and impairment as located not in (or only in) individual bodies but rather as "off" the body of the individual within a network of family and kin relationships. It is useful in this context to consider the different types of stigma in relation to the configuration of domesticity - rather than individual agency as the focus of attention we could see how the individual comes to be embedded within the domestic or excluded from it and its implications for policies on public health.

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[3][3] See Veena Das, The act of witnessing: Violence, poisonous knowledge and subjectivity. In *Violence and subjectivity*, ed. Veena Das, Arthur Kleinman *et al*, Berkeley: University of California Press, 2000: 205-226.

[4][4] See Veena Das and Renu Addlakha, Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture,* 2001, 13 (3): 511-531

Stigma, Aesthetics, and the Importance of Face

An examination of the genealogy of the ideas of defect shows how defective and stigmatized subjects were historically produced on the intersections of various kinds of norms – especially those of femininity and normalcy. For instance, Campbell[5[5]] has argued that that contingent discursive inscriptions of "defect" could imperil the life projects of female subjects even in the absence of any functional disability or impairment of the senses simply because of the way that diseases were seen to mark the individual female subject. She gives the example of eighteenth century European women whose small pox scarred faces were rendered as "damaged" and who were then assimilated to other stigmatized and damaged subjects[6[6]]. A recent study by Weiss of new born infants in Israel who were abandoned by parents because they were "appearance-impaired" though they did not suffer from any functional disabilities, points to the conditional character of parental acceptance of stigmatized subjects[7[7]]. Her analysis shows that parents felt that their social lives would be thrown into peril for which they blamed their impaired infants – even when persuaded by social workers to bring such infants home for short periods of time, they ended up hiding them in dark corners of the house because they wanted to "protect" their other children from contact with an impaired sibling. What is remarkable in Weiss's account is not that parents expressed despair or even hostility, but that all other emotions such as hope, sorrow, or regret were censored out of their narratives. Thus the tyranny of norms of appearance that stigmatized facial defects seems to have thrown these infants out of domestic citizenship into the domain of the state as the only sphere in which their rights, including rights to life, could be defended.

[5[5]] Jill Campbell, Lady Mary Wortley Montageu and the "glass revers'd" of female old age. In *"Defects": Engendering the modern body*, edited by Helen Deutch and Felicity Nussbaum. Ann Arbor: University of Michigan Press.

[6[6]] We need to be wary of cross-cultural generalizations here. Historical scholarship suggests that in India, at least after the seventeenth century, small pox came to be seen as a visitation from the goddess Sitala and the victim defined as sacred and taboo rather than a bearer of negative stigma. Though the suffering of the disease was not minimized in the culture as evidenced by the various rituals to propitiate the goddess so that she did not possess anyone, the typical association of stigma with guilt and shame was not part of the experience of the disease. See Ralph W. Nicholas, the goddess Sitala and the epidemic smallpox in Bengal. Journal of Asian studies, 1981, (1): 21-44.

[7[7]] Meira Weiss, Ethical reflections: taking a walk on the wild side. In Small wars: the cultural politics of childhood, Ed, by Nancy Scheper –Hughes and Carolyn Sargent. Berkeley: University of California Press, 1998.

In an earlier study Arthur Kleinman discussed the narratives of six patients suffering from various kinds of stigmatized diseases or disfigurement, five of these patients were treated in his psychiatric clinic in Cambridge[8][8]. The stories of these patients range from the severe constraints on life experienced by a man with a facial disfigurement despite support from his family, to life lived in complete isolation by a man who suffered brain injury that led to a critical diminishing of his cognitive capabilities followed by a divorce and separation from his family. Kleinman's main concern was to show the intersubjective nature of experience in chronic illness - it is remarkable that even in the clinical setting of individualized therapy, he is able to show the ghosts of family dramas in the individual narratives of his patients. But because of the context in which therapy was offered we do not get a sense of the politics of family and community within which such dramas took place. What, for instance, would account for the complete severing of the relationships in the latter case? The power of his description shows that for the patient, the suffering of the disease was indistinguishable from the suffering of social isolation and stigma. If we had access to the other members of the family we may have also learnt how they lived with the memory of this ruptured relationship.

The stories of such betrayals of persons with stigmatized conditions need to read along with other stories in which parents and caregivers negotiate norms, form associational communities to learn and provide support and act in the public domain to influence state policy and science[9][9] In these cases the family appears to form a protective envelope around the child and caregivers repeatedly contest the collective representations that would assimilate such children to stigmatized subjects. It is especially interesting to see the new developments around what Paul Rabinow calls "bio-sociality", i.e. the forming of associational communities around biological conditions to influence state policy and science[10][10]. Yet the capacity of a group to use social capital for dealing with adverse biological conditions is strongly dependent on other social conditions such as education – a public good, but not equally available to those who occupy a lower position in the socio-

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[8][8] Arthur Kleinman, *The illness narratives: Suffering, healing and the human condition. New York: Basic Books, 1988.*

[9][9]See especially, Rayna Rapp, *Testing women, testing the fetus: the social impact of amniocentesis in America*. New York: Routledge, 1999. Rayna Rapp and Faye Ginsburg, Enabling disability: Rewriting kinship, reimagining citizenship. *Public Culture*, 2001. 13 (3).

[10][10] Paul Rabinow, *Making PCR: A story of biotechnology.* Chicago, University of Chicago Press, 1996.

economic hierarchy. So what are the other ways in which family and community might become supportive rather than hostile to its vulnerable members?

In some of my own work on this subject, I have argued that while the attention to associational communities calls upon the individual as the subject of a liberal political regime, there is another sphere of sociality relating to the politics of domesticity, which operates outside this domain[11][11]. In the domains of family and kinship stigmatized conditions are seen as a matter of *connected body-selves* – hence they give rise to a different kind of politics from the politics of associational communities. Rather than a confrontation between state and community, here we find the family pitted *against* the kinship group which tries to put pressure on it so as to contain the stigma to the individual body rather than allowing it to "spread" to the whole kinship group. Various strategies are then put into place through rumor and gossip for separating the stigmatized individual, confining him or her to a limited sociality, or giving only limited recognition when included in the collective life of the group. While in such cases families may not have the "biocapital" to engage with state and science in the way described by Ginsburg, Rapp and Rabinow, they do need to use other resources of the state to confront and defeat the social pressures generated by local communities. I have elsewhere given the example of a Hindu Punjabi family who risked their social capital in order to find a sexual and reproductive future for their daughter stigmatized by a facial disfigurement by aligning themselves to the state and claiming the rights promised in such legislative actions as the Civil Marriage Act [12][12]. I am therefore wary of assuming a sharp separation between face to face communities as repositories of the moral and the state as a source of rational policy, for it seems to me that it is not in individual institutions (e.g. family and community *or* the state and bureaucracy) but in their *alignment* that resources to address problems of social exclusion resulting from stigmatized conditions may be found. As we saw earlier, we cannot treat the domain of family as that of unconditional parental acceptance but nor can we treat the state as uncontaminated by social norms regarding stigma. Rather it is in the way that new patterns of sociality around biological conditions emerge through an alignment of

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[11][11] See Veena Das, Violence and the work of time. In *Signifying identities*, ed. Anthony Cohen, London: Routledge, 2000 and Veena Das, The act of witnessing: Violence, poisonous knowledge and subjectivity. In *Violence and subjectivity*, ed. Veena Das, Arthur Kleinman *et al*, Berkeley: University of California Press, 2000.

[12][12] See Veena Das and Renu Addlakha, Disability and domestic citizenship: Voice, gender, and the making of the subject. *Public Culture,* 2001, 13 (3): 511-531.

domesticity with the state that we can find salutary examples of the way in which the social exclusion resulting from stigmatized conditions has been contested.

Body, danger and shame

While illness narratives of persons with disability generally deal with the feelings of damage and low self-esteem as a result of the loss of the autonomy of the body, there is a far greater weight placed on the feelings of guilt and shame in the case of stigmatized conditions. Consequently a big question that looms in the narratives of stigmatized illnesses is the question of innocence. Writing on his experience of disability, Robert Murphy wrote, "Disability is not simply a physical affair for us; it is our ontology – a condition of our being"[13[13]]. Borrowing the metaphor of the primal scene from Freud, he argued that any confrontation of people in which there is some great flaw leads to feelings of guilt and shame. This, for him, was related not only to the social opprobrium of the others, but also to the subjective feelings that the body impairment is a punishment for repressed, elusive and forbidden desires. Thus stigma became for him, not a byproduct of disability, but its very substance. On the level of social relationships the disabled person presents a counterpoint to normality – Murphy's bitter lament was that the very humanity of the disabled person is made questionable.

It seems to me that Murphy's acute analysis captures the important point that the changed body image in stigmatized conditions seems to trigger broader fears of violation of sexual norms and hence dangers to a moral universe. Some support for this can be found in Hanne Bruin's analysis of the discursive formations around the condition of leprosy in Tamilnadu in India where she found that the major part of the stigma of leprosy arises because of a fear that the stricken person has violated sexual norms such as that of incest or the sexual and reproductive norms of caste hierarchy[14[14]]. It is important to note though that stigma seems to be associated not with the disease as such but with the bodily deformities that come after the patch stage if the disease remains untreated. The person afflicted with leprosy, however, has to start "reading" the disease right from the onset of first symptoms

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[13[13]] Robert Murphy, *The body silent*. New York: Henry Holt, 1987.

[14[14]] Hanne M de Bruin, *Leprosy in South India*: *Stigma and strategies of coping*, Pondy papers in social sciences. Pondicherry: French Institute, 1996.

-noticing changes in the body and devising strategies of concealment. Patients have described their fears that if their disease were to become known they would be cast out of the moral community because of the presumption that the deformity of the body was a punishment for infringement of sexual taboos. The entire discourse of anxiety that surrounds the stigma of deformed bodies thus is about reduction of sociality, exclusion from moral community as well as subjective feelings of guilt and shame. Being cast out of the social community coupled with a diminished sense of worth reduces the capability of the afflicted person to seek help even when this is in objective terms, easily available.

It is in this context that we can see the great anxiety reported in the case of stigmatized diseases with questions of “innocence”. In a study of leprosy patients in Delhi and in Kanpur Dehat in Uttar Pradesh, Surabhi Tandon reports that patients worry enormously about what kind of moral taboo they could have violated[15][15]. She found that the predominant claim on the part of patients was that their illness was not a result of any moral fault and that if the illness was indeed a punishment, then it could only have been because they had *inadvertently* broken a social norm. However, Tandon also shows that intricate patterns of domestic and village politics entered the decisions of patients on whether they could continue to live within the same moral community or whether it was necessary for them to move out and to form new communities. However, it was the visible changes of the body and the stereotypes about patients having no fingers and toes, open wounds, fallen nose bridges, etc. that were read as “evidence” of the moral transgressions rather than the disease itself. With greater awareness about the role of multidrug therapy in curing leprosy and reconstructive surgery, even in areas with endemic leprosy such as Kanpur Dehat, the aspect of stigma became much less pronounced in the discussions with patients and their caregivers[16][16]. This should warn us against tendencies to reify “culture,” to assume that there are a set of unchanging values that inform local worlds - for medical technology can make a decisive difference in how a disease is culturally perceived. In the case of Kanpur Dehat a large number of patients were recruited for a clinical trial of an immuno-therapeutic and prophylactic vaccine and interestingly this helped to bring the disease into the open. Villagers reported that the easy mannerism of the doctors and social

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[15][15] Surabhi Tandon, *Social and individual aspects of chronic illness: A case study of leprosy*, Unpublished Ph.D. dissertation of the University of Delhi, 1999.

[16][16] See Surabhi Tandon and Mukul Kumar, Ethnography of a vaccine trial: the trajectories of documents and objects. *Economic and Political Weekly (special issue on Social science and immunization)*, February 2000.

workers in the field when they touched or interacted with known leprosy patients did more to allay fears about the disease than any verbal messages. This is an interesting case demonstrating that it is the style of care as much as its content that makes people read the disease in a different way.

The fear of contagion

The notion of stigma and contagion are theoretically distinct concepts– the first refers to the experience of being marked on the body by a condition that sets one apart and the second to the potential for a condition to be transmitted from one person to another – but in the everyday life of communities these two concepts tend to slide in each other. Even in the case of a disability such as quadriplegia resulting from a neurological disorder, Murphy noted that social encounters were fraught with danger because "people acted like it is catching". Murphy experienced it as a contamination of identity. As I have stated earlier, though, the stigma of disability, impairment and body disfigurement is not treated as an individual affair in societies that place less importance on the individual as a locus of value – instead it is treated as a matter of connected body-selves. This does not mean that we can neatly divide societies into individual-centered societies and socio-centric societies as some have suggested. Rather it is a matter of seeing how stigmatized diseases lead to the drawing of boundaries within the domestic and its immediate environment of kinship and village or neighborhood community. The case of tuberculosis presents an important example of the way that notions of stigma and contagion slide into each other in the villages and urban neighborhoods in low-income countries. This, I argue, has implications for the way that the biological course of the illness comes to be related to its social course.

Susan Sontag's analysis of illness as metaphor shows us the romantic notions regarding the character of TB patients in nineteenth century Europe and the ambivalence with which such patients were viewed[17][17]. While elite discourses on tuberculosis in the South Asian subcontinent might have been influenced by such notions of the relation between tuberculosis, melancholia and artistic creativity (especially in literature and film), in the everyday life of communities the stigma of tuberculosis exposes the patient to dire

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[17][17] Susan Sontag, *Illness as metaphor*, New York: Vintage, 1978.

risks from the way that the biomedical system(s) and the institutions of the state treat those who have suffered from the disease.

In a critical analysis of the biomedical discourse on tuberculosis, Paul Farmer has shown that there is predominant tendency to attribute failure of compliance to the "beliefs" of the patients and the stigma attaching to the disease.[18[18]] Farmer presents a survey of the literature to show that the agency of the patient is highly exaggerated in this discourse – patients often fail to comply because there are inadequate supplies of medicines in treatment centers, or because of severe constraints on their time and money. Yet the biomedical discourse creates a geography of blame in which their failure to comply is attributed to their beliefs about tuberculosis. Do the institutions of the state and science themselves contribute to this stigmatization of the disease?

In an ongoing study of health practices of families in low-income neighborhoods in Delhi, we found that while tuberculosis undoubtedly created new boundaries within kinship and community, there were other major deprivations patients faced from the institutions of the state[19[19]]. This was because of the way that notions of stigma and contagion were collapsed into each other in local administrative and social practices. Thus, for instance, some children who had to drop out of government schools because of tuberculosis in one year were refused admission in the next year even after they were cured, on the grounds that they could spread the disease. At least in part because of the way that people who had suffered from tuberculosis were treated in the community and in the DOT centers, they themselves experienced recurrent fears that the disease would never be fully cured and tended to attribute any subsequent symptoms of weakness, sadness, fevers, unspecified pains to the fact that they once had tuberculosis[20[20]]. In an overall environment of poor regulation of pharmacies, some of our respondents reported taking TB medication whenever they had cough or fever as a prophylactic because they were scared that the disease may recur and that they may be blamed for this. The collapsing of the categories of stigma and contagion points to the fact that the social course of the disease may extend beyond its biological course so that each notion reinforces the other. Stigma is seen as

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[18[18]] Paul Farmer, *Infections and inequalities*, Berkeley: University of California, 1999.

[19[19]] This is longitudinal study of health seeking behavior among 300 households in seven neighborhoods in Delhi directed by R.K. Das and myself.

[20[20]] I owe this point to Laura Pincus who has interviewed a number of young women in a low-income locality in Delhi who were cured by biomedical standards but continued to feel that their illness would never be cured. TB patients in our sample in Delhi express same or similar fears.

contagious and conversely a disease that is contagious may be seen as marking a person with stigma. It also raises the question of how science and state might contribute to the perception of a disease as stigmatizing and how that is related to existing fault lines of race, ethnicity and gender discrimination.

Stigma, silence, and the geography of blame

A major concern in relation to stigmatized disease is that the social marks of inferiority or blemish may lead patients and their caretakers to conceal their disease. This has serious consequences for both the health of the individual and the containment of infectious diseases for the population. It was mentioned earlier that bearers of stigmatized diseases are seen as a great danger to the community because of the assumptions that they have somehow violated the moral taboos, especially those on sexuality. This leads to feelings of guilt and shame. Obviously then diseases that directly relate to sexually tabooed behavior bring questions of guilt and shame much more to the surface. However it is not only individuals who are targeted as the bearers of stigma and blame in the case of sexually transmitted diseases but there is also a political geography of blame that comes to arrange the world in terms of "guilt" and "innocence". The case of sexually transmitted diseases such as syphilis and AIDS provides telling examples of the way in which stigma of various kinds comes to be configured together in informing the public discourse on stigmatized diseases.

The first decade of the twentieth century was a period of intense concern with sexually transmitted diseases and the appearance of the social hygiene movement in North America. It is interesting to observe that not only in popular discourse but also in the biomedical system, a distinction was made between "venereal insontium," i.e., the venereal disease of the innocent versus the venereal disease of those who were held guilty because of sexual misconduct. Allen Brandt argues that this distinction had the effect of dividing victims into those who were deserving of medical support and sympathy and others who were not, because they were guilty of sexually promiscuous behavior[21][21]. It is not surprising to see that the latter category slides into stereotypes fuelling a fear of new

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[21][21] Allen M Brandt, From social history to social policy. In *Aids: The Burdens of History*, ed. Elizabeth Fee and Daniel M Fox. Berkeley: University of California Press, 1988: 147-172.

immigrants, urban populations and blacks. Brandt shows that the assumption of guilt led to the most pernicious violation of the civil rights of groups identified as guilty sources of this disease. It is uncanny to see that the end of the century saw very similar processes in relation to the discursive formations that developed around AIDS.

In the initial years of the North American epidemic AIDS was widely termed as the "gay plague" – the discourse on the disease was hooked into the cultural concerns with sexual morality and especially with homophobia. Because of the rich cultural response by the gay community, at least in important urban centers in North America, the taboo on silence was broken. Yet the very power of this cultural critique of homophobia may have served to draw attention away from other forms of discrimination that the anxiety on AIDS brought to the fore.

Susan Sontag claimed in 1988 that in North America AIDS evoked less pointed racist reactions than in Europe or Soviet Union where the African origin of the disease was much more stressed[22][22]. In his influential work on Aids and accusation Paul Farmer pointed out that as early as 1981, members of the Haitian community denounced the racism inherent in the stigmatization of Haitians *qua* Haitians as "AIDS-carriers"[23][23]. Through a careful analysis of the popular media and scientific representations in this period, Farmer shows how the discourse on AIDS was tied to questions of immigration with a strong denial of the evidence that many of the Haitians who were reported to have brought in HIV infection into the country were likely to have contracted it *after* their arrival here. Just as in the case of syphilis earlier, there was stigmatization of high risk, marginal groups so that in many public pronouncements there were powerful assumptions about culpability and guilt of these populations.

Questions of guilt and innocence seem to haunt other instances in which the question of HIV infection has been addressed. In a little appreciated corner of the epidemic there has been a controversy regarding those patients with hemophilia who were infected with contaminated blood. As early as 1983, an article in New York Times Magazine referred to the disease as if it were more "poignant" when it attacked nonhomosexuals then when it attacked homosexuals. In recent hearings on patients infected by contaminated

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[22][22] Susan Sontag, *AIDS and its metaphors*. New York: Farrar, Strauss, and Giroux, 1988.

[23][23] Paul Farmer, AIDS and accusation: Haiti and the geography of blame. Berkeley: University of California Press, 1992.

blood products, the collective narrative tried to carve out a space of innocence from which patients could separate their own affliction from those whose AIDS was blamed in the popular culture on personal behavior such as unsafe sex, or IV drug use[24[24]]. The very process of fighting stigma in such cases reaffirms the way in which personal affliction is made to fold into the stigma of belonging to marginal groups.

There are other contexts in which ideas of innocence and their counterpoint – notions of blame- have been used to open up other kinds of suspect moral spaces. Thus for instance, just as there is a discourse of the geographical origin of AIDS in North America and Europe that is hooked into discursive formations on race and racism, so there is a discourse in non-Western countries that reverses this geography of blame. For instance in the popular representations of AIDS in India and several other non-Western countries, the epidemic was attributed to the moral degeneration and the lax sexual morality of the West. This allowed even Government representatives and scientists to claim in the early nineties that AIDS would never be a problem in India because Indians were protected by a rigid and puritan sexual morality. Even when the problem was grudgingly acknowledged in the late nineties, popular conceptions of AIDS continued to link it with either marginal groups such as sex workers or with "westernized" women from the feminist movement despite mounting evidence of the high rate of infections among monogamously married women whose plight till recently was completely ignored.

Scholars concerned with public health discourse and critical epidemiology have repeatedly pointed out that notions such as patient's beliefs have often led policy makers and biomedical practitioners to "blame" the patient for failure to comply with medical regimes. I hope this analysis shows the intricate connections between the public and the private domains in addressing problems of stigma. While the importance of stigma and the consequent social exclusions in local moral worlds is very important to document, it is equally important to realize that threats of new diseases create anxieties that can be expressed through a political geography of blame not only in the popular discourse but also in the scientific discourse.

The role of the state

[24[24]] For an incisive analysis of this case, see Arthur Kleinman, The violences of everyday life: the multiple forms and dynamics of social violence. In *Violence and Subjectivity, op.cit.*226-242

Fears of contagion and stigma have often led to denial of basic rights. We can document this by the well-known cases of sexually transmitted diseases. An important example of how prejudices produced by stigma can function in state sponsored terror is provided by the example of leprosy patients who were sought to be compulsorily segregated despite scientific recommendations to the contrary during the colonial period in India. This case is useful to demonstrate the relation between contagion and state formation though it also points out that colonial states did not exercise draconian powers simply as a matter of course.

Take the debate on incarceration of leprosy patients in India in 1890 when a Commission was appointed to investigate the "disease of leprosy in India". The members of the Commission included eminent medial scientists nominated by the Royal Society for Surgeons and the Royal Society for Physicians. The Commission, after completing its investigations concluded that leprosy was a disease *sui generis* and that it was not a form of syphilis or tuberculosis despite "ateological analogies" with the latter. It said that the extent to which leprosy was contagious was exceedingly small and hence no imperial law need be passed to implement compulsory segregation. It stated "No legislation is called for on the lines of either segregation or interdiction of marriage with lepers." The Commission did recommend that lepers should be prohibited from practice of professions that involved handling of food or drink or from providing services as barbers or washer men but they thought that segregation should be on a voluntary basis. Accordingly they recommended that municipal bye laws would be enough to handle the necessary state provisions that were needed in this case – undue force in the form of compulsory segregation, they thought, would be unjust and would cause untold misery.

The Executive Committee of the National Leprosy Fund rejected the recommendations of the Commission in 1892. The Executive Committee found that the scientific evidence regarding most cases of leprosy having occurred *de novo* was not conclusive. Hence it emphasized the importance of maintaining colonies for compulsory segregation of lepers and also required that "if leprous patient be retained at their homes at the express wishes of their friends then separate lodgments would have to be provided." It further stated, "For carrying out the above, in addition to funds, legislative authority is needed to take up the vagrant sick, to remove the sorely diseased who is insufficiently guarded at home, and at times to enforce continued isolation of the infected until medical sanction of liberty be granted."

This case shows that it was not scientific evidence available in that period but notions of stigma that informed colonial policy, though these concerns were hidden under the overall concern with public health and public order. The state turned out to be a major actor in the production of stigmatized subjects- far from a rational state correcting the credulous public - its own policies were likely to have contributed to the legitimization of the stigma surrounding leprosy and to criminalize the patients through draconian laws.

The role of the state in establishing a connection between stigmatized disease and criminality is further attested in the case of mental illness. The emergence of new technologies of power in eighteenth century Europe through which the state tried to control its unruly population has been the great theme of Michelle Foucault's rendering of disciplinary power. Foucault's inattention to the colonies leaves considerable scope to add greater complexity to the issue of disciplinary power. Earliest asylums for the insane were established in India between in 1787 and then 1795 to incarcerate European soldiers showing signs of insanity. In the period between 1856 and the end of the nineteenth century, asylums were established for Indians. As in the colonies of Africa, where these came to be established in the beginning of the twentieth century, asylums functioned as adjuncts to the penal systems.

In a recent analysis based upon archival records James Mills[25][25] has shown that though the number of those incarcerated in the asylums in India was not large in itself, the discursive formations around madness were part and parcel of the wider politics of the colonization of bodies in which the capacity to perform approved labor was established as an important sign of normality. Thus insanity and criminality had a great deal to do with refusal to perform forms of labor that were approved by the state. While it is clear that labor did not structure asylum regimes in India in the same way as the prison, yet irregular, peripatetic, and "unproductive" occupations were likely to come under one or the other form of disciplining by the state. Thus prisoners who refused to perform productive labor

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[25][25] James H. Mills, *Madness, Cannabis and Colonialism London:* St. Martin's Press, 2000. Also see James H Mills, Reforming the Indian: Treatment regimes in the lunatic asylum in British India, 1857-1880. *Indian Economic and Social History Review,* 1999 (36).

were frequently transferred to asylums where their perceived aversion to labor was counted in support of the diagnosis of insanity. Mills observes that readiness to resume labor was seen as evidence of recovery and that the discourse of madness easily slides into the perceived faults of the Indians as a group and the asylum regime, like colonialism itself, as a project for reforming the Indians.

In this context it is important to consider not only the institutions but also the systems of knowledge through which such slippage between individual affliction and group stigma was sustained. Jock McCulloch has analyzed the colonial archives on asylums in Africa and the literature on ethno psychiatry to show how discussion on causes of insanity among African patients inevitably led to the stigmatization of the whole culture[26[26]]. He quotes extensively from respectable journals in this period to show how in evaluating African patients there was a strong tendency to stigmatize African culture that was held responsible for creating a climate of fear because of widespread belief in witchcraft. Africans were further accused of having lack of individuality, of rigid adherence to rules and absence of responsibility, which led them to be sexually promiscuous and socially unreliable. Ethno psychiatry played a role in stigmatizing independence movements in Africa. Thus the scientific discourse on stigmatizing illnesses followed the fault lines of race and ethnicity. It is quite likely that the state thus played an important role in legitimizing social exclusion of the insane though as McCulloch himself notes, hospitals and asylums were likely to be used only for those who already fell into the category of "social refuse".

Unfortunately it would be far too easy to assume that postcolonial societies have been able to overcome this pernicious equation between stigma, crime and guilt. It was as late as 1987 that the Indian Lunacy Act, which had little concern with the welfare of the mentally ill, was changed to the Mental Health Act in India after considerable pressure from the mental health community. The National Commission of Human rights in India, since 1996, has been pressing the various state governments to take steps for the amelioration of the condition of mentally ill patients who are languishing in prisons. The conditions in private institutions for the confinement of the mentally ill in small towns continues to be dismal though there is some reported improvement in the government run

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[26[26]] Jock McCulloch, *Colonial psychiatry and the African mind*. London: Cambridge University Press, 1995.

institutions after strictures from the Supreme Court in early nineties. As recently as last month (i.e. August 2001), 25 mentally ill patients were burnt to death in a fire in an asylum in a small town in Tamilnadu where enquiries confirmed that there were fifteen private asylums in the city and that it was normal practice in these to keep the inmates tied. Even in a country as affluent as the United States, the Justice Department has stated that one-fifth of the estimated 191,000 inmates of prisons who were identified as mentally ill were not receiving any treatment.

State and Science

As we saw in the case of AIDS activism, the homophobia in popular discourse as well as in the institutional practices of state and science was challenged in the responses by AIDS activists. Their challenge also brought out the way in which notions of stigma inform policy and programs of the state. It is salutary to realize that the community discourse on stigma is not isolated from the discourses of the state. In the previously colonized countries such as India, the discourse on stigma bore the marks of colonial legislation. Thus the Vagrant Lepers Act, the Lunacy Act, the Contagious Diseases Act, the Cantonment Act, were all designed to protect public spaces from the presence of stigmatized bodies. The Vagrant Lepers Act still forbids begging by “lepers” – the language used is not neutral and points to the way in which patients suffering from Hansen’s disease were often abandoned and had to fend for themselves by begging and were criminalized for this. In general, the legislation has lagged behind scientific breakthroughs. For instance though the prevalence rate of leprosy in India declined from 50.2 per 10000 in 1994 to 6.2 per ten thousand in 1996, yet changes in legislation on various debilitating conditions for such patients has been very slow. This is true for many other countries. In the case of Japan, the Kumamoto District Court recently ordered the government to pay 1.82 billion yen in compensation to 127 Hansen's disease patients for violating their personal rights by segregating them under the 1953 Leprosy Prevention Law. The court said the former Health and Welfare Ministry was negligent for failing to alter its isolation policy. This could have been done by 1960, when it had been confirmed that the disease was curable The legislature was also held responsible for failing to amend relevant laws, including scrapping the Leprosy Prevention Law. The government policy of isolating Hansen's disease patients in sanatoriums ended in 1996 when the Leprosy Prevention Law, which the Kumamoto court deemed unconstitutional, was abolished. (As reported in Mainichi Shimbun, 2001)[27[27]].

The above instances are important for devising strategies to deal with the stigma While such stigmatized groups as patients with Hansen's disease, prostitutes and other high risk marginal groups, ethnic minorities, new immigrants may not have the biocapital to fashion a cultural response to stigma in the manner of gay activists, the removal of pernicious laws and administrative practices would be an important step in low income countries to deal with such issues.

Concluding summary

In conclusion I would like to draw attention to the following salient points with regard to notions of stigma, and its relevance for public health interventions.

- While much of the literature in the West emphasizes the stigma as production of spoilt identity and its management, in other parts of the world stigma along with its related concepts of contagion and defect are seen as problems of connected body-selves.
- The moral anxiety around stigma arises from its connection with taboo – deformed body selves are especially seen as marks of violation of sexual and reproductive taboos.
- Discourses on stigma are deeply implicated in the fault lines of racism, sexism and other forms of discrimination, but it is important to treat culture not as a set of

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[27[27]] One can multiply examples of the ham handed approach to legislation in the case of new stigmatizing diseases such as AIDS. In India both legislation and adjudicatory practices of lower courts have passed through phases in which AIDS patients were sought to be imprisoned, foreign students had to submit to compulsory testing and courts have been hesitant to endorse the rights of patients with HIV infection to be treated. The situation has changed slowly mainly due to the work of various organizations such as the Lawyers Collective and the Naz Foundation. The first AIDS case in India that entered the courts was the case of Dominic D'Souza who was incarcerated in a TB sanatorium under the (now repealed) Goa Public Health Amendment Act, 1986. Lawyers Collective successfully represented a person known as MX in the literature who was a public sector employee and who lost his job when he was found to be HIV positive in the course of a routine health examination. He was reinstated by the Bombay High Court. In general AIDS activists have concentrated their fight for repeal of Section 377 that penalizes intercourse between consenting men as "against the order of nature". Such laws are often used by police to harass and intimidate homosexuals and those testing positive. I am grateful to Lester Coutinho for a discussion on this point.

shared, unchanging beliefs but as framed by contests and adjustments. The notion of domestic citizenship provides an entry into thinking of the ways in which culture is mediated and recrafted by contested engagements in the sphere of domesticity.

- A major way of contesting stigma in recent years has been through formation of associational communities – not all forms of stigma though may be addressed in this manner since this depends crucially upon social capital and “bio-capital”.
- In many previously colonized countries state legislations have lagged behind scientific knowledge in changing forms of legislation that was enacted in colonial contexts and was designed to protect colonial interests rather than the interests of the patients. Since the institutions of the state are equally implicated in production of stigmatized subjects, judicial activism towards reform of pernicious laws especially with regard to sexually transmitted diseases and mental illness would be an important resource for marginalized groups to deal with stigmatized conditions.