

STAYING POOR: CHRONIC POVERTY AND DEVELOPMENT POLICY

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POVERTY AND DISABILITY with special reference to rural South Asia
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1. Introduction: the Taboo

If measured by resources committed and by rhetoric, by the quality of analysis and by data availability, alleviating the condition of being disabled is the lowest priority on state welfare agendas in practically all underdeveloped countries,¹ arguably in all countries.

Being disabled as a result of an impairment (a loss of function) handicaps the individual, but the private individual is also handicapped by the way disability has been treated in discourse. There are at least three aspects to this treatment.

The first concerns public policy. The 1993 Human Development Report of UNDP contains compendious data on all aspects of the human condition, with the exception of disability on which there is nothing at all (UNDP, 1993). Influential typologies of vulnerability ignore the disabled (e.g. Cornia, Jolly and Stewart, 1985). On the social welfare agenda of India, poverty, caste and gender push disability to the foot. This low priority can be explained by the political weakness of disabled persons and by the high perceived economic costs and low perceived political benefits (or the high political opportunity costs and low economic benefits) of a state response to problems which are administratively anomalous and transactions-costly. It is logical to expect that such a reasoning would operate more powerfully on the welfare agendas of poor countries than it does of rich ones.

¹ Vietnam, Afghanistan and Zimbabwe are exceptions, probably because of the impact of disability related to war and conflict.
(M. Miles, Pers. Comm., 1994).

The second is the intellectual neglect accompanies political neglect. Disability signifies that which a person suffering impairment cannot be and cannot do. A.K. Sen did not develop his powerful concept of capability - what people can be or do - for the incapacities that follow from impairment (Sen,1990). Furthermore, the notion of development as capability expansion carries the implication that there is a developmental ceiling for people whose capabilities cannot under any circumstances be expanded ². It is a different point that development as capability expansion or freedom focusses upon the exercise of positive freedom and residualises negative freedom³. For most disabled people to experience, let alone expand, their positive freedom, both the capability to function and the negative freedom of non-disabled people have to be constrained. A reduction in the negative freedom of others would be a necessary precondition for the achievement by poor disabled people of equality in 'basic capabilities'. The latter are also denied to the entire set of poor people by their condition of poverty.

The third neglect interacts with the other two, granted that both policy and theory for social development are notoriously data-constrained. ⁴ Globally comparable data on disability does not exist. Country-specific information is more often than not out of date. India is a good example because it well exemplifies the political and social conditions of poor and of disabled people and because it has data which is available in English which is thought to be of better quality than that of other countries otherwise similarly situated.

In India, it is estimated that about 332 million of a population of 884 m in 1991 exist below the official poverty line.⁵ A different but overlapping population, some 270 millions, belong to scheduled castes and tribes, collectively labelled as 'weaker sections'. Both socio-economic groups qualify for targetted developmental aid and the latter for positive discrimination. From clinical evidence it is currently thought that between 3.7 to 6 per cent of the total population suffers from locomotor, visual, communication-related disability or from mental retardation. This is a larger proportion than that estimated as severely malnourished (2.7%) (Subbarao, 1992). At least 60 m were likely to be disabled then in 2001.⁶ The lives of their families, those people affected indirectly by disability amount to perhaps 4-5 times as many : as many as 240 - 300 millions.

² While for a physically disabled person, remedial social technology ranges from porters and sedan chairs to motorised wheelchairs, there is no technical response at any price which can make some types of blind people see (even if there are means by which their environmental perceptions and capacities to communicate can be improved).

³ Positive freedom is freedom to be and to do; negative freedom is freedom from external control, hindrance or co-ercion.

⁴ See for example UNDP, 1993; McGillvray, Pyatt and White, 1995.

⁵ (ed) Harriss et al. 1992.

⁶ Thomas 1992a, Helander, 1993; see also <http://www.indiatogether.org/health/opinions/jabidi1.htm>.

The lack of knowledge of disability as a development problem and of the interaction between poverty and disability amounts to a taboo, it is not surprising to find that non-clinical, field-based literature on this subject is very patchy. It is often characterised, understandably, by the same 'special pleading' visible in the much larger literature on social aspects of nutrition.

2.1 The Complex Condition of Disability

Disability is a relative term because cultures define differently their norms of being and doing. Disability may be identified by appearance ('ugliness', albinism, the absence of (even a functionally unimportant) digit), while impairments recognised as disabling in western cultures (mild to moderate mental retardation, club foot) are often not treated as disabling (Helander, 1993, p12). In South Asia, social deviancy is classified by many local people as a disability, as is an ascribed condition such as being outcast from the caste system. Some see economically oppressive, socially tyrannical and politically disenfranchising forms of work such as child labour and bonded labour as disabling. Yet others find (female) infertility or the delayed onset of menarche a serious impairment. Conditions such as asthma and TB, which are classified as 'sickness' are experienced as disabling in agrarian economies still based substantially on manual labour.

Development can then be seen as a liberation from such social disabilities and from systems of technology, reason and value producing them. We will use the term 'disability' here in the more targetted and clinical sense popularly accepted in the west, but mindful of its analytical restrictiveness and of the ethnocentricity that lurks beneath the apparent universalism.

As a form of deprivation, disability is intractably complex. Yet the concept of 'disability' is a crude political label akin to that of being 'black'. Disability is a probabilistic type of development problem - different from those which are location, income or gender specific. It also takes a perverse form in that the proportion of the population deprived by disabilities increases with development.

Just as there are demographic and epidemiological transitions so there is a disability transition⁷. Impairment forms a continuum from 'ability' to a range of kinds, combinations and intensities of incapacity. Medically and some times for the purposes of legal claim, they are distinguished according to type (visual, aural, locomotor and mental) and severity.⁸ The condition may be static or it may change progressively. That disability

⁷ Causative factors are increases in life expectation and increased survival rates from disabling accidents and diseases. To the extent that domestic development is socially uneven, the disability transition will display its full complexity across social classes within a given nation.

⁸ ICIDH-WHO (1980) Hammerman and Maikowski, 1981; Helander, 1993).

increases dependence, not only among children and the elderly but also among adults of working age is clear. It also may force those on whom the disabled person depends to be more socially dependent in turn. That disability causes poverty is incontrovertible. But disability affects the non poor as well as the poor and the social and economic costs of a given disability will differ according to social or ethnic group, gender, age and economic status.

2.1 Disability and Poverty

Disability and poverty are closely related. In OECD countries, for instance, disability causes poverty through the vicious pincer of labour-market exclusion and inadequate social transfers, and despite formally protective law (Russell, 2001; Barnes, 1991; Hammerman and Maikowski, 1981). In a country with mass poverty, poverty also causes disability (Narsing Rao, 1990). The mechanisms include malnutrition, inadequate access to inadequate preventive and curative medical care, and risks of accident or occupational injury. Poverty interacts with caste, family size and the quality of parental or adult care to create the condition of **simultaneous deprivation**. A. Sen finds that simultaneous deprivation is further compounded by a syndrome composed of ideological reinforcement, punitive experience, psychological extinction, stimulus deprivation and a cognitive and verbal development which especially affects what is beautified as the ‘participation’ in the economy of low caste groups : the terms and conditions on which they are forced to labour. This syndrome sets up barriers to the participation of all types of disabled people but especially mentally disabled people and especially girls. The positive association between incapacity, disability and poverty is confirmed in a census of three villages in Tiruvannamalai District of Tamil Nadu (Table 1).

Table 1: Households with and without chronically sick and/or disabled members, Tamil Nadu, 1993

	Village 1		Village 2		Village 3	
	a	b	a	b	a	b
No of Households	270	75	217	45	96	41
Av income Rs/yr	12400	7650	13500	11300	9500	7000
% of Households below Poverty Line*	51	54	36	60	51	62
% of Households with under Rs 5,000 assets	31	35	26	47	24	30
% of Households with greater than Rs 100,000 assets	20	10	2	3	25	15

* computed at Rs 6,000 for a household of 4 members

a = without chronically sick or disabled members

b = with chronically sick or disabled members

Source: Field Survey, 1993

Working with peoples' own definition of chronically sick and disabled, between 17-30 per cent of households had at least 1 chronically sick or disabled member - there being wide intervillage variation. A slightly higher proportion of these households were below the income poverty line and had assets under Rs 5,000 than households without disabled members and lower percentages of households were in the top assets category.

Chronic sickness and disability seems to affect both short term and long term poverty. Households with chronically sick and disabled people tended to have smaller family sizes, smaller operational landholding sizes, lower grain consumption from own production and greater market dependence for food. Working members put in fewer days on average into their own agricultural production and more in non -agricultural production than did 'healthy' households. Those with sick and disabled members had livestock of lower value than those without, and higher levels of debt.

But others argue an inverse relation between income-poverty and the prevalence of disability on grounds that mortality from disability is greatest among the poor. There is evidence for a **disability transition** during which disabilities due to malnutrition and infectious/contagious disease are eradicated. They are more than offset by reduced mortality rates, the increased survival of para- and quadri-plegics, and by increases in disabilities due to trauma and old age, such that the total incidence of disability increases (Mohan, 1988). There is international evidence for the inverse relationship (Helander, 1993).

This latter evidence, however, is no excuse for non-interventionism because raised levels of mortality result from the economic incapacity of poor families to sustain the lives of disabled members.

2.2 War-Related Disability

Throughout the developing world, injuries from war or conflict and their aftermath (landmines) disable significant numbers of people. One study in Afghanistan **before** the era of rule by the Taliban put the figure of those disabled by war at 1.6 m people, 12 % of the population. Three quarters of these were young men of working age. When wars are protracted and the fortunes of sides in contention fluctuate, the privileged social status of young fighters often unravels and is replaced by indifference. This had already happened by the mid nineties in Afghanistan. War-disabled men faced a sudden and sharp loss in their productive capacities; their skills were often irrelevant to the limited range of work available; its frustrations frequently went on to destabilise marriages with inter-generational effects upon children. The reproductive burden of the kin group has been altered and the burden of increases in wear and tear and 'externalities' falls upon women. In consequence, the time women devote to child care, agriculture or horticulture drops, reducing current and future income. War-disabled young women face crises of (un)marriagability.⁹

2.3 Disability and the Environment

Two aspects of the environment seem to be important to an understanding of disability and poverty. Factors in both the physical environment and the social, spatial environment may predispose towards disability.

With respect to the first aspect, the Indian National Sample Survey's 36th Round in 1981 showed that certain states (Bihar and West Bengal in the north; Maharashtra, Andhra Pradesh and Tamil Nadu in the south) have much higher than average concentrations of disabled people (ISS,1988,p.

⁹A. Aziz, 1995, 'Sen's Capabilities and the War-Disabled', M.Sc. thesis, Queen Elizabeth House, Oxford.

20). The prevalence of locomotor handicap is strongly associated with agriculturally advanced regions; that of deafness and dumbness with northern regions and Himalayan valleys. The incidence of leprosy is strongly concentrated in tribal regions of Bihar and West Bengal and in Tamil Nadu and Andhra Pradesh in the south (ISS, 1988, pp.14-17, p. 19).

Research on the 1981 Census data for Uttar Pradesh confirms that disabilities have strong environmental geographies. The state was classified into contiguous regions of high, medium and low prevalence. High prevalence regions had over 14 times the state's average prevalence. This concentrated distribution is attributed to environmental factors (lack of iodine), diseases (poliomyelitis and lathyrism), social and economic factors (low levels of urbanisation, high levels of food insecurity, poverty and 'criminal offences' which incapacitate victims) (Shukia, 1990).

With respect to the social environment, it has been argued that the prevalence of disability is higher in urban than in rural areas. But while the rate of urbanisation is 25 per cent in Uttar Pradesh, only 9 per cent of disabled people were urban in location (Krishnaswamy, 1990). In Uttar Pradesh, highly urbanised districts had the lowest prevalence of the censused disabilities, the lowest incidence of poverty and the highest incidence of health care infrastructure (Shukia, 1990).

2.4 Disability and Gender

The material and ideological subordination of women is so well documented that disabled women are expected to be severely socially disadvantaged. The disabled woman has been depicted in graphic terms as suffering 'multiple handicap. Her chances of marriage are very slight, and she is most likely to be condemned to a twilight existence as a non-productive adjunct to the household of her birth...(she may be) the object of misplaced (*sic*) sympathy... or she may well be kept hidden in order not to damage the marriage prospects of siblings; alternatively she may be turned out to beg' (Coleridge, 1993, p. 154).

Yet World Bank evidence for India shows women surviving childhood as having a 10 per cent lower disease burden and losing fewer disability-adjusted life years from disability than do men (World Bank, 1993). Disability-related mortality may be higher among girl children and women than it is among men. Anyway, this female 'advantage' is not distributed evenly across clinical disabilities. The 1981 disability ratio was highest (at 1789 males per thousand females for locomotor disability, and 1788 for speech disability). It was 1211 for the hearing disabled and only 699 for visual disability where (despite the fact that over 3 times more men than women are born blind) the sex bias is antifemale (ISS, 1988, p14,p16). Female advantage may thus be translated into female disadvantage by socialisation and discrimination.

2.5 Disability and the Life Cycle

Globally, the prevalence of moderate to severe disability increases from 2 per cent in infancy to 55 per cent in the over 80 age groups. Thus increased life expectation carries with it the 'paradox' of increasing disability prevalence rates.

In India, while 6 to 10 per cent of all disabled people were born with their disability, children are especially vulnerable to disabilities resulting from malnutrition and communicable diseases. Children

with disabilities are more likely to die young than they are in developed countries. So some forms of disability in India relate to age in a manner opposite to that of the global model. It has been estimated that 75 % of the mentally retarded for instance are under the age of 10 and only 4 % are over 20 (Sen, 1992, p. 255). Dumbness behaves similarly. Other forms of disability, such as loss of aural and visual acuity behave according to the global model and occur within the geriatric population with far greater frequency than in the general population. ¹

So, disability identifies a big social category, like poverty does. But complexity is central to disability and this often medicalised social condition cannot be reduced to one criterion for evaluation in the way that until recently poverty has been appraised and evaluated for policy purposes, however crudely and controversially, by income. Just as social factors, such as gender, age, caste (and status as a fighter), and economic factors, such as poverty, condition disability (sometimes in opposite ways to those which have been modelled), so environmental factors, such as the disease ecology and physical resources, and political factors, such as the distribution and type of health care, play a spatial role in the creation and perpetuation of disabilities

In 1995, the anthropologist Susan Erb and I embarked on a field study of three villegs between Walajabad and Kancheepuram in Chinglepet District of Tamil Nadu to answer three questions: i) what do disabled adults do in a rural society depending on hard physical labour? ii) what are the costs and economic impact of disability and iii) what do disabled adults need? These are villages where an NGO has been active in the causes of countering violence against scheduled caste women, education for girls and women and the organisation of claims by poor people to their economic and social rights. They had not been active on issues of disability and development. Our work was eventually published: Susan Erb and Barbara Harris-White 2002 *Outcast from Social Welfare : Adult Disability, Incapacity and Development in Rural South India*, Books for Change, Bangalore (bfc@actionaidindia.org).

We used a *social model* of disability in which incapacity is related to environments and social situation and which seeks to discover the causes and effects of incapacity in an open way.

3. Incapacitation in the Rural Economy

The three villegs (Thammanur, Kalur and Vitchanthangal) each comprised caste settlements with separate scheduled caste hamlets ('colonies'): totalling 540 households (1753 adults). Half of the households are landed and the majority of all of them depend to some extent on agricultural wage-labour. Five per cent of households with land and looms control 48 per cent of the total income while 43 per cent, mainly labouring households, account for 18 per cent of total income of these 3 villegs. The scheduled caste population amounted to 23 per cent. Some 15 per cent of households, none of which were scheduled caste, worked in the non farm economy (mainly in silk saree weaving and in its ancillary industries). The latter activities accentuate economic inequality.

3.1. Incidence, Types and Causes

While disabled children were very rare,² some **6.5** per cent of adults - 156 people - described themselves as disabled/ incapacitated, and practically all in adulthood (Table 2). Their incidence was evenly distributed across the genders (47 per cent male and 53 per cent female) but biased

towards the caste population. (86% of disabled people were from the 68 % of the total population who are caste hindus, with only 16 per cent from the 32 per cent of scheduled caste adults who admitted incapacity.) However, the lower incidence of disability in the *colonies* was due to the different social context of landlessness and poverty in which **disabilities have to be much more severe to be publicly recognised as such**. Within the caste settlements, disability occurred in proportion to the distribution of intra-village castes reflecting no type of caste bias. ***Most disability encountered was mild to moderate in form and the result of old age, occupation-related diseases and accidents and illness***. The range of disabilities affecting rural workers was vast. Conditions which would not be deemed disabling according to western medical definitions were seen to result in disability, due to indigenous definitions of health/ill-health and/or inability to work productively in an agrarian society heavily dependent on physical vitality.

Almost all disabled people were physically impaired, having visual loss, orthopaedic disorders and hearing impairments. Mental disability went practically unnoticed in women, a comment on the nature of the work they are required to do. **Old age tends to be defined by the onset of incapacitating conditions** rather than by years alone. But many of the conditions which incapacitated people from work were the product of occupation-related conditions. Since the landless agricultural labour force spends years staring at the reflection of the sun in flooded paddy fields, as they tend seedlings in nurseries, transplant and weed, it is hardly surprising that such workers suffer sight impairment in early middle age.³ The public space of villages without electricity supplies is dark and dangerous at night. Roots, unembedded water pipes, rutted path ways and holes in the ground can damage limbs with consequences on work that we will track. Silk looms are installed in huts which, in an effort to keep out heat, are not only poorly ventilated but also very poorly lit. Then, conditions not disabling according to western medicine can be incapacitating in the universe of rural work, notably because they make sustained physical effort painful: sterilisation was quoted several times in this regard (medical treatment is regarded as potentially disabling); ulcers and other causes of chronic stomach pain; deep-seated warts (disabling pain in the foot); asthma (and other causes of dizziness) etc..

Table 2: Rural Adult Disability 1995: Populations

	Total		Disabled	
	Male	Female	Male	Female
Thammanur				
Village	358	347	35	48
Colony	169	157	9	4
Kalur/Vitchanthangal				
Village	239	237	22	26
Colony	162	84	8	4
TOTAL	928	825	74	82

Disability, chronic sickness and pain were seen to elide. In these villages, then, disability is an affliction, usually physical in nature which results in the partial or complete incapacitation of a household member. The moderate nature of most impairments means that even if incapacitated people could gain access to treatment, their condition denies them eligibility for state and NGO

facilities. In any case, these, confined to severe cases, tend to be complements to, rather than substitutes for, one another.

4. The Social Construction of Disability

Gender, caste and class condition both the perception of incapacity and a household's response to it (Erb and Harriss-White 2002). While slightly more women than men acknowledge themselves as disabled, **domestic work hides both the condition and its impact**. Women's domestic work is a compulsory prior which is difficult to negotiate. We might infer from the social relations behind these village statistics that considerably more women may be disabled than are men, but that **fewer women than men may be able to declare themselves incapacitated**. Fieldwork showed that women also recognise themselves to be disabled at a more advanced stage of incapacity than do men. Even when forced to withdraw from agricultural labour, half of the disabled women continue to perform domestic work. There is no relaxation in the domestic division of labour.

In a similar way, **scheduled caste people have to be more severely disabled** than inhabitants of the caste settlement before they will publicly acknowledge their infirmity.

Class also determines the type and intensity of work, exposure to environmental hazards, poverty and the capacity to 'come out' as disabled. By and large, landed disabled people are less severely incapacitated than landless agricultural labourers. Not only is the latter's work more energy intensive and hazardous but their work hours are longer (Jackson and Palmer-Jones, 1998).

4.1 Treatment and Response

The entire process of 'care' is also socially constructed and extremely male-biased (Table 3). While 53 per cent of caste males seek and obtain some kind of treatment for their condition only 11 per cent of (more severely disabled) SC females can do this; 26 per cent fewer (more severely incapacitated) caste women get any kind of treatment and their care is 75 per cent less costly on the average than that of men. Only men had treatment involving surgery. Among scheduled caste people, even though their economic participation rates are much more gender balanced, 80 per cent fewer women than men get access to treatment. The seasonality of visits to clinics does not relate to the timing of onset of an incapacitating condition, rather it reflects labour demands and the prior compulsions of wage work. Treatment is more frequent in the agricultural slack season and is usually part of a multipurpose journey.

Table 3: Services Received by Gender (1995)

	Males			Females		
	Main Settlement	Colony	Total	Main Settlement	Colony	Total
Total Disabled	57	16	73	74	9	83
Total Treated	30	9	39	29	1	30
Percentage of all Disabled Adults Receiving Treatment	53 %	56 %	53 %	39 %	11 %	36 %

5. Costs

The costs of being disabled have three components: i) the direct costs of treatment, including the costs of travel and access; ii) the indirect costs to those who are not directly affected (called 'carers' in the west) and iii) the opportunity costs, the income foregone from incapacity. The direct annual costs of incapacitation vary staggeringly from the equivalent of 3 days' work to that of 2 years' work for an average household of able bodied agricultural labourers with 2 adults and 2 children (ALHH) in which a male income averaged Rs3,000 and a female one Rs1,800 per annum. Direct costs depend on the type and severity of the incapacity. The **average annual direct costs**, Rs 1,200 in 1995, **are equal to 3 months' income** for an ALHH. The average orthopaedic treatment amounts to 5 months' labour for an ALHH. Added to this are opportunity costs, totalling an average of Rs 1,800, that is 4 months' income for an ALHH. The average direct and opportunity costs of incapacity for a woman are 25 per cent of those of a disabled man. This gender difference in the treatment of disability is due to i) gender ideologies expressed in gendered differences in the evaluation of severity, ii) biased access in treatment and social response, iii) gender roles stressing the subservience of woman, iv) differences in earnings from gendered labour markets and contractual arrangements and v) the dominant role of unwaged female labour in the indirect cost component.

Indirect costs to 'carers' arise in only 4 per cent of cases where the disabled person cannot complete their daily living tasks unaided. None of those who help with these personal tasks have ever earned wages. Yet this addition to their domestic work burden has effectively excluded all of them from 'participation' in the labour market. All the 'carers' are female and one is disabled herself. It is not uncommon in these admittedly rare instances to find a girl removed from school for such work, in which case she is denied future returns to education. We have not attempted to compute this income stream foregone.

5.1 The impact on households and on the rural economy

For **half** the incapacitated men and **two thirds** of the women, **the costs of treatment prohibit any treatment at all**. Most of these people continue to work more or less dysfunctionally in the agricultural labour market and in their homes. Others interpret the treatment improperly, do not complete it, share prescriptions, practices which lower both the direct cost of the response and its therapeutic impact. Even so, such households tend to be dosed with debt and make strong efforts to minimise the economic dependence of disabled members.

In these villages, **being incapacitated does not seem to affect social standing as judged by others**: disabled people are not socially excluded or ostracised on account of disability, almost certainly because of its onset during adulthood. But disabled people have fewer days of employment and lower wages when they work. Sight is more important than hearing to casual agricultural labour. An inability to contribute to the household economy definitely affects social status (hence there is a double incentive to minimise economic dependence: loss of status and avoidance of debt). Status is of particular importance in the lives of elderly, incapacitated men. Disabled people are penalised not so much by stigma in the eyes of others but by shame in their own eyes.

The onset of disability is an economically disabling event for the entire household. The loss of a complete male income pitches an ALHH without savings immediately into debt. The loss of a complete female income leads to an income loss such that an average ALHH cannot feed itself adequately (assuming expenditure on calories amounts to 85 per cent of the reduced income). In over half the cases of male disability and over a third of those of female disability, households are set on a track of downward economic mobility as a result of the loss of earnings of the incapacitated person.

The sequence of coping and survival tactics bears a strong family resemblance to those modelled for the process of famine:

- i) drawing down of savings;
- ii) incurring of emergency debt - typically in the region of Rs 500 - from local neighbours;
- iii) increased debt from moneylenders and pawnbrokers;
- iv) female assets (jewels) disposed of before male assets (land/ house site);
- v) begging from neighbours (and therefore caste folk).

In this process of destitution, blind, landless widows without supportive children are the worst off.

We have attempted to summarise and stylise the evidence given us so as to calculate the likely costs of disability to a household and to the rural economy (see Tables 4 to 6). Table 4 uses the evidence on the numbers of adults involved, their gender and socio-geographical origins in Table 2 to compute the proportions of disabled adults incurring the three types of cost due to disability and the estimated average direct, opportunity and indirect costs for the year 1995. In Table 5 the impact of the full cost of an average disabled person has been estimated for two types of households, the first simulating the mass of the labouring population and the second simulating the loom-owning agrarian elite. Here our data begin to come to life. They show how an agricultural labouring household cannot bear the full costs of a disabled male without being plunged into considerable debt, while the full costs of a disabled man or woman in a loom owning household are a substantial drain while not threatening its elite status. The income gap between labouring and elite household (a factor of at least 6 in the absence of disability) rises to a factor of 25 for disabled adult women and towards infinity for men because of negative income streams in the poor household.

Disability is the more serious an economic shock the poorer the household in the first place and it is economically differentiating.

In Table 6 there is an estimate of the social costs of disability to a rural economy, simulated by data aggregated for the three caste villages and three scheduled caste colonies.

Table 4: Costs of Disability to a Household, 1995

Costs	% of disabled people affected		Rs
Direct:			
	men	57%	1200
	women	36%	864
Opportunity:			
	men	47%	3,900-12,000 ¹ av: 7545

	women	35%	1800
Indirect		4%	1800

1: the average is weighted according to estimated differences in incomes before and after disablement in actual occupational distribution of disabled men (0.39 agriculture + 0.44 agricultural labour + 0.15 silk + 0.03 other (mill work) = (2613+2451+1800+324)

Table 5: Differentiating Impact of Disability: Full Costs

	Rs
Agricultural labouring household income	5700
with disabled male	- 6900 = -1200
with disabled female	- 4464 = 1236
Silk weaving household income	36000
with disabled male	- 15000 = 21000
with disabled female	- 4464 = 31536

Table 6: Costs of Disability to Rural Economy, 1995

(based on TVK villages and colonies)

	n	%	av income (Rs)	total income (Rs)	%
a) RURAL ECONOMY					
Landed agricultural hh	251	48	9,200	2,309,200	33
Ag. Wage Lab + Millwork	18	3	12,600	266,800	3
Agriculture plus looms	10	2	27,500	2,750,000	39

Landless Agric labour hh	228	43	5,7000	1,299,600	18
Loom owning hh	18	3	36,000	648,000	9
	525			7,029,480	

b) SOCIAL COSTS OF DISABILITY

Direct costs	males	(d.p. x 0.57)	50,616
	females	(d.p. x 0.36)	25,505
Opportunity costs	males	(d.p. x 0.47)	249,999
	females	(d.p. x 0.35)	51,660
Indirect costs		(d.p. x 0.04)	11,232
			389,012

c) LOSS TO RURAL ECONOMY 5.5%

Set against this simulated economy we see in Table 6 an estimate of the economic losses from locally defined disabilities. The largest components of the social losses are those pertaining to men. **The direct and opportunity costs of disabled women are one quarter those of disabled men**, due, first, to gender ideologies leading to the undervaluation of the severity of female disabilities, second, to gender roles stressing subservience and support and, third, to gender differences in wages in the labour market. In addition the small component of indirect cost is borne by women and girl children. **The cost to society of disability which directly affects 8% of adult men and 10% of adult women and which indirectly affects the lives of a third of the rural population, connected by ties of close kinship and living in the same households is about 5.5 per cent.** ⁴

This can be read in several ways. There are those who would read this as a small loss. Disability does not stop rural Indians from working. Disability is not much of a development problem. It is perfectly reasonable then that disability should be outcast from the social welfare agenda as it operates in practice, even if it is included in policy rhetoric.

The value of micro-level village research lies in its capacity to provide an alternative interpretation and one we believe is more reasonable. First it is a development problem: a proportion of gross product needing to be reduced. **Losses to incapacity are exactly on a par with estimates of current productivity losses due to undernutrition, losses interpreted as 'huge'.** ⁵ Second, it is a partial

and underestimated representation of the social costs of incapacity due to the important invisible contributions made by women in not acknowledging their own impairments in the first place, by their unwaged reproductive domestic contribution to the economy and by their unwaged care for disabled relatives. Third, this 5.5 per cent can be read as underestimated because so many disabled scheduled caste and caste men from landless and hardly-landed households are coerced by poverty into continuing to labour for wages. Fourth, the loss of productive income due to disability and incapacity reflects the low wages paid to both male and female agricultural labour – and thus the low opportunity cost of the agricultural income foregone.

Irrespective of the exact type of disability (and many disabled people have moderate-degree combinations of impairments which confound the notion of type), there are social rules regulating the relations between impairments, work compulsions, expert treatment, social assistance and domestic care. These rules work through land relations and control over productive resources, through caste, gender and household composition. These rules further lead to a distribution of costs due to disability which are highly unequal and in which those most dependent upon the labour market for income, those anyway most socially discriminated against, and those who are gender-subordinated, work without social acknowledgement until they are much more severely impaired than others. Landless scheduled caste women are particularly more vulnerable to exclusion from any treatment. Their household poverty is then exacerbated by **the heavily male biased recourse to narcotics and/or alcohol for the relief of pain and of feelings of guilt, a form of therapy which can cost a labouring household between 10 and 40 per cent of its income. This cost was not included in the calculation of the costs of disability to the rural economy.** Nor were the opportunities and incomes foregone by child substitute labour. Nor was the invisible, unwaged household productive and reproductive work of disabled women. Nor was their unwaged work as carers, except for the tiny minority of women caring for completely dependent disabled people. All these costs are unknowable, but they are not trivial. If included, they would in all probability more than double the social costs of disability.

However this statistic is interpreted, the needs of disabled rural people are worth listening to. For the first type of interpretation, it is necessary to understand ways of increasing the physical efficiency by which disabled people participate in the economy, for the second, to distinguish male and female needs, for the third, to establish the rights of the disabled poor to social security and their real access to it and, for the fourth, to look at ways of creating livelihoods, improving the terms and conditions of employment and fighting for what the ILO (1999) calls ‘decent work’ for disabled people.

6. Poor rural disabled peoples' needs : goods and services

The fieldwork reported here has several implications for any polity concerned with rural poverty and distress. First, there is a need for schemes to increase the physical ease of economic participation. For this, male and female needs can be distinguished. Disabled women need access to **treatment**, pure and simple. Women did not receive treatment for four reasons. First, the costs of restorative equipment and clinical consultations were considered prohibitive. Second, the treatment of women's disabilities was perceived as a very low domestic priority. Thus, even when households did have access to liquid cash, it was used preferentially for agricultural investment or debt repayment. Also, if a disabled woman were to seek treatment, an adult would be subtracted from child care and domestic chores leaving their

responsibilities unfulfilled unless there were other women to replace her, a complaint repeatedly voiced by male household heads. Third, many women appeared unaware of how to gain access to restorative equipment. Finally, there appeared to be a strong mistrust of allopathic medical practitioners regarding surgical treatment. Cataract operations had been recommended to four visually disabled individuals who were unwilling to invest either time or money in the surgery due to the demonstration effect of the failure of such surgery on neighbours. To these rural people, **medical treatment itself runs a high risk of being a disabling activity.**

Both men and women need **simple restorative equipment** (spectacles, crutches, hearing aids). For most poorly sighted people, their visual disability was too mild to qualify them for any government schemes enabling for free access to ophthalmic tests, spectacles and facilities for the repair and maintenance of restorative equipment. It is altogether another matter that most had no idea such schemes existed or that they might have rights of access to them. The provision of spectacles would have allowed them to undertake household or agricultural chores with greater ease and efficiency, and, in more than one household, might have allowed them to return to wage work and to participate more fully in domestic and social life.

The second need was for **short term assistance in the form of loans or grants** to cover access to health care or equipment: of up to Rs 500 in 1995 prices. Disabled people are more vulnerable to shocks and to costlier 'wear and tear' in day to day living. This expressed need is also a disguised plea for better public health care. Conditions which incapacitate workers are poorly recognised and treated. Private health care is much preferred, even by the poor. Inappropriate medicine may be prescribed; half prescriptions obtained because of the poverty of patients; medication is often shared between people with the same condition. Poverty leads to quackery by doctors being to some extent matched with delinquency by patients. By the standards of micro finance such loans would be extremely small and pose acute problems, not of default but rather of administration costs.

The third need was for **information, bureaucratic transparency and intermediation**, most specifically for access to social assistance entitlements which most commonly takes the form of a pension of Rs 75, four kilograms of rice per month, plus an annual allotment of two sets of new clothing a year. These pensions can be for disabled, destitute, widowed or elderly individuals. Most commonly disabled people gain access to old age and widow's pensions. Our research showed that the eligibility criterion for a pension for disability is extremely harsh. For disabled people who are unable to bring an income into the household, a pension can be a valuable social and economic asset. The government pension form is a standard document requiring information on the individual seeking the pension, and details of their disability or their specific social, age and health status. Access to state pensions requires both a birth certificate and the signature of a doctor supporting the applicant's claim. Because the majority of disabled villagers did not fulfil the official conditions for Handicapped Pensions, they were often compelled to pay medical doctors large bribes to secure their support and signatures for other kinds of Pension or Benefit (which they saw as interchangeable). These bribes varied from two week's to seven month's worth of a female agricultural labourer's income. However, given that the pension is equivalent to two thirds of a woman's income, **the bribe might be as much as the equivalent of 14 months' worth of pension payments:** another swingeing indirect cost of disability which we did not include in our calculation of social costs. In these three villages, 34 women had secured a widow's

pension with payments of bribes ranging from Rs 50 - Rs 1,000. **There were no individuals in the settlements who were receiving 'Handicapped Pensions'.**

6.1 Other Forms of Public Action :Uncivil Society

NGO activity is thin on the ground. One christian charitable organisation provides shelter and a peaceful environment for disabled women. Certain medical doctors with a philanthropic disposition give free treatment for incapacitation (just as they do for other conditions). The international business-cum-philanthropic organisations (Lions and Rotary Clubs) organise peripatetic eye camps providing cataract surgery, eligibility for which is determined by the rural social networks of the largely urban professional and businessman members. Of the concerns of the literature on disability and development: one, income generation, is not seen by respondents as relevant to them and the second, empowerment, is seen as a problem of governance rather than of local social and political attitudes. Of the concessions for disabled people in education and employment, there was of course no sign in these villages, not so much because of the dereliction of duty by the state as because so few of the rural incapacitated were eligible through their medical and educational status and their age. Depending on the type of disability, between 1 - 3 % of medicalised and therefore severely disabled people have access to either an NGO or the state.

Incapacity and disability in these rural areas is dangerous to the individuals concerned and their households. It causes efficiency losses in the economy and is the object of egregious neglect. Feminist economists have persuasively argued that structural adjustment, in its reductions of public expenditure, places a disproportionate compensatory burden on women, and in the domestic arena (see for example, Elson, 1992). With respect to rural incapacity and disability, this process of cuts in public expenditure has been bypassed, for there was no public expenditure in the first place.

7. Conclusions

Evidence from the research area shows that medicalised and state-legitimated definitions of disability are but one way that societies understand the concept of disability. The people we studied do not recognise or experience disability in terms of the classifications or severity categories of the medical model. Policy based on the medical model overlooks the **large number of mild to moderately disabled rural adults** incapacitated from rural work.⁶ Conditions not disabling according to rigid medicalised definitions **do** result in disability according to local understanding and experience of health, ill-health and well-being. For individuals living in a society where economic productivity depends on physical and manual dexterity even a small loss of these skills can result in downward mobility. For the disabled people in the region we studied, social and economic standing is measured against capacity to work. **Disability is predominantly defined according to the dual compulsions of household maintenance and the labour market.** It is anything preventing men and women from being part of the social reproduction of a labour process producing paddy, groundnut and silk sarees.

Types, combinations and intensities of disability have a varying social impact on the disabled individual and their household in light of age, gender, household status, class and wealth, caste and existing state provisions in terms of rights and social welfare assistance. The majority of adults in these villages were only mild to moderately afflicted according to medical parameters. The ramifications for access to service provision for this doubly marginalised population is their exclusion from both private voluntary sector and government programmes intended to improve their standard of living. **Until voluntary and**

government service providers modify their perception of who the disabled are and what their needs are , the private and social costs of disability will remain high.

Caste and gender remain highly significant determinants of disability. Women, especially scheduled caste women, receive low priority for treatment. Identity as a disabled woman or as a disabled *colony* inhabitant indicates a much higher degree of physical debilitation than is the case for disabled caste men. For women, this is the result of prevailing social perceptions that even when women are unable to earn an income due to incapacitation, they are still required to carry out domestic work.

The lower incidence of disabilities in the *colonies* results from the different social context of landlessness, poverty and the compulsions of work in which disabilities have to be much more severe to be publicly recognised as such. Not only does the condition of disability cause poverty by means of direct, indirect and opportunity costs, but impoverished households are fundamentally more susceptible to disabling circumstances via malnutrition, defective access to preventative and curative medical care, exposure to disabling disease and an increased risk of occupation-related accident. Disability combines with poverty to create situations of downward mobility which are more strongly experienced within scheduled caste households. Caste, family size and reduction in economic opportunity converge with disability to create a condition of simultaneous deprivation. **Disability is differentiating.**

7.1 Disability and Poverty as Development Issues : the Structure of the Difference

It is society which is disabling rather than people who are disabled. Development indicates the social change which weakens the forces 'disabling people', households and classes. If gender and environment can become intellectual paradigms, why not also disability which raises fundamental questions about human welfare?

Disability, like gender, is a cross-class phenomenon, even if relations of disability manifest themselves differently by class. Like gender, the relations of disability are reinforced by social divisions of labour and by ideologies, which appear natural but are in fact historically constructed and which in practice are remarkably similar to gender-based ideologies of subordination. Like environmental issues, disability has a weak constituency. Like caste, ethnicity and old age, disability is a distinct kind of passport to exclusion, intensified with poverty, but cutting across poverty. Like poverty, disability entails political remoteness, but the second deprivation cuts across the first.

Gender and the environment have become influential development narratives not only because of the work of new social movements but also because of the impacts of feminist and environmental professionals - and of social movements created and/or sustained by them in **developed** countries - upon international development institutions. Their current priority is the result of institutional engineering. The same constellation of forces is needed for disability, yet the constraints on disabled people as activists are far greater and more debilitating than those which curb the opportunities of women. The support of non dominating professionals, the local state, and even international aid agencies is the more necessary.

Disability is a highly varied condition. Complexity is key to understanding its social consequences. It should not be and cannot be reduced to a single criterion for the purposes of policy formulation. By doing the latter, the specific needs of individuals may be overlooked in favour of policy transfers from the west addressing the perceived needs of crudely categorised, severely disabled people.⁷ As important as the provision of restorative equipment is to disabled rural Indians, so also are small loans and access to social assistance; last but not least the improvement of rural health care and rights of access to all these public goods and services.

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1. Jackson, 1988; Desai, 1990; ISS, 1988, p. 15-18

2. **Either children are not disabled or they do not survive.**

3. **This is not to argue that Vitamin A deficiency does not also play a part in causing such blindness.**

4. **5.5% of production is not a minor problem. Von Oppen's 3-state spatial equilibrium simulation of gains to trade and liberalisation in agriculture in India gave the result that complete free trade increased gross production by (only) 2-3 per cent (von Oppen, 1978).**

5. **Lawrence Haddad, IFPRI, Pers. Comm, 2001. See Gillespie and Haddad, 2000 for Pakistan and Vietnam. Estimates of GDP lost by protein-energy malnutrition, iodine and iron deficiencies vary from 2.4 to 4 %, effectively halving growth rates.**

6. **The medical model also focusses on the individual rather than the social and physical environment and on the body rather than the social being (Lang, 2000).**

7. For a critique of the latter see Lang, 2000.