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**THE POLITICAL ECONOMY
OF DISABILITY AND
DEVELOPMENT
WITH SPECIAL
REFERENCE TO INDIA**

by Barbara Harriss-White

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◆ Preface

The condition of being disabled is at the bottom of the development agenda, unrecognized as a problem for development and absent from the United Nations human development reports. It also goes untheorized: many of the incapacities that follow from impairment cannot be reduced without a corresponding reduction in the capabilities of non-disabled people. Along with neglect in policy and theory goes a deep factual neglect. The data about the conditions of disability are of low quality, patchy, often seriously out of date and sometimes the result of special interest or pleading.

The author of this paper seeks to review the relationships between disability and development. India is taken for illustrative purposes, because of the relative abundance of material, and the exemplary nature of the social and economic institutions in which disabled people are embedded and of the political neglect with which they are treated. It would seem that there are more seriously disabled people in India than there are seriously malnourished ones.

As a form of deprivation, disability is intractably complex. It is a probabilistic condition, understood in locally specific ways, associated with economic losses directly to the disabled person, indirectly to their household and to future generations. It is both caused by and causes poverty and inequality. It is also a development paradox, increasing in frequency with increases in life expectancy. Its recognition and impact depend on gender, social class and caste, age and location.

Institutions producing and reproducing disability are also analysed in the paper, including the household and locality; missionary and religious organizations; other non-governmental organizations; markets for equipment, treatment and labour; and the state. The author then examines the way a technocratic policy discourse has evolved in India, as well as how it has been translated into legal provision and implemented through organizations created by the state and supplied with human and financial resources. She claims that there is no coherent agenda, no recognizable state obligation or means whereby needs can be translated into practical claims. Resources are on a declining trend, and the state fails to regulate the market or private sector and NGOs.

Policy options in an era of structural adjustment and reforms to social sector expenditure are also reviewed, including Community Based Rehabilitation, social movements of collective action, and the cases for developmental state action. The kind of agenda for disability which would be consistent with the recognition of an imperfect obligation is mapped out.

The paper concludes by arguing that the same types of progressive international and national forces that have worked to create gender and the environment as influential developmental issues are needed for disability. But because the constraints on disabled people as activists are far greater and more debilitating than those curbing the opportunities of women, the support of non-dominating professionals and of international aid agencies is even more necessary.

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March 1996

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Director

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1. INTRODUCTION: THREE TYPES OF 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 developing countries,¹ arguably in all countries.

The 1993 **Human Development Report** 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 et al., 1987). On the social welfare agenda of India, poverty, caste and gender push disability to the foot. This low priority can be explained in public choice theoretic terms 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 calculus would operate more powerfully on the welfare agendas of poor countries than of rich ones.

Intellectual neglect accompanies political neglect. Disability signifies that which a person suffering impairment **cannot** be and **cannot** do. Sen has not developed his powerful concept of capability — what people can be or do — for the incapacities that follow from impairment (Sen, 1990). His notion of development as capability expansion involves the exercise of positive freedom and residualizes negative freedom.² But for certain disabled people, certain types of capability expansion are simply not possible.³ For most disabled people to experience, let alone expand, 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 is a logical precondition to the achievement by poor disabled people of equality in the list of otherwise “basic capabilities” which are denied to the entire set of poor by their condition of poverty.

The third neglect interacts with the other two, granted that both theory and policy for social development is famously data-constrained.⁴ Globally comparable data on disability do not exist. Country-specific information is more often than not out of date. We can use India as an example because it well exemplifies the political and social condition of disabled people and the institutions affecting their behaviour and welfare, and because it has data

¹ Viet Nam, Afghanistan and Zimbabwe are exceptions, probably because of the impact of conflict-related disability (M. Miles, personal communication, 1994).

² Positive freedom is freedom to be and to do; negative freedom is freedom from external control, hindrance or coercion.

³ While for a physically disabled person, remedial social technology ranges from porters and sedan chairs to motorized 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).

⁴ See for example UNDP (1993) and McGillivray et al. (1995).

available in English which are thought to be of better quality than the data of other countries otherwise similarly situated.

In 1991, it was estimated that about 332 million out of India's population of 884 million existed below the official poverty line.⁵ A different but overlapping population of some 270 million persons belonged to scheduled castes and tribes, collectively labelled as "weaker sections". Both socio-economic groups qualify for targeted developmental aid and the latter for positive discrimination. The 1981 census of India was the first and last twentieth century census to enumerate the disabled as "blind" "dumb" and "crippled". Extreme criteria of impairment were used.⁶ Only 1.1 million were identified as disabled. The National Sample Survey Organisation (NSS) also surveyed "the disabled" in 1981 and subdivided them into four classes — visually handicapped, communication handicapped, locomotor handicapped and mentally handicapped — which were less restrictively defined than in the census.⁷ The census took no account of the mentally handicapped and neither the census nor the NSS estimated those afflicted with leprosy. The aggregate results of the NSS survey are presented in table 1.

Table 1
India: Number of disabled persons, 1981 (in millions)

| Type | Total | Per cent | Rural | Urban | Male | Female |
|------------------|-------|----------|-------|-------|------|--------|
| Locomotor | 5.4 | 40 | 4.3 | 1.1 | 3.5 | 1.9 |
| Visual | 3.4 | 25 | 2.9 | 0.6 | 1.4 | 2.0 |
| Hearing | 3.0 | 20 | 2.4 | 0.5 | 1.6 | 1.3 |
| Speech | 1.7 | 12 | 1.4 | 0.4 | 1.1 | 0.6 |
| Physical* | 11.9 | — | 9.6 | 2.2 | 7.0 | 5.1 |
| Per cent | — | — | 81 | 19 | 57 | 43 |

* more than one of the four categories

Source: NSS, 1983

These are great underestimates. From clinical evidence it is currently thought that 3.7 per cent of the total population suffers from locomotor, visual or communication-related disability, or from mental retardation (Thomas, 1993a). This is a larger proportion than that estimated as severely malnourished (2.7 per cent) (Subbarao, 1992). It is thus likely that at least 32 million people were disabled in 1991.⁸ The families of disabled persons, those people affected indirectly by disability, likely amount to 4-5 times as many: perhaps 130 million persons.

Non-clinical, field-based literature on this huge but virtually taboo subject is patchy, and may be characterized very understandably by the same "special pleading" visible in the much larger literature on social aspects of nutrition.

⁵ Harriss et al. (1992).

⁶ Blindness required complete loss of sight in both eyes. Dumb people were unable to speak and cripples had lost both arms and/or both legs.

⁷ Visually disabled could not count the fingers of a hand correctly from a distance of three metres in good daylight. The dumb suffered voice defects. The deaf were categorized into moderate, severe and profound. Locomotor disability, defined as the lack or loss of the normal ability of an individual to move her or himself and objects, was recognized to have several causes: paralysis, deformity, amputation and joint dysfunction. Hunchbacks and dwarfs were included among the locomotor disabled (NSS, 1983).

⁸ Thomas (1992a); Helander (1993).

◆ 1.1. 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 recognized as disabling in Western cultures (mild to moderate mental retardation, club foot) are often not treated as disabling elsewhere (Helander, 1993:12). 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 social impairment. Conditions such as asthma and tuberculosis, which are classified as “sickness”, are experienced as disabling in agrarian economies still based substantially on manual labour. Development can be seen as a liberation from such social disabilities and from the systems of technology, reason and value producing them. We will use the term “disability” here in the more targeted and clinical sense popularly accepted in the West, but remain 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 is also perverse 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 transition.⁹ Impairment forms a continuum from “ability” to a range of kinds, combinations and intensities of incapacity. Medically and sometimes for the purposes of legal claim, they are distinguished according to type (visual, aural, locomotor and mental) and severity.¹⁰ The condition may be static or it may change progressively. That disability 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.

With respect to **gender** for instance, while the Indian sex ratio is famously anti-female biased (Dyson, 1992), those women who survive appear to suffer less gender disadvantage in the prevalence of clinically disabling conditions, with the exception of blindness (ISS, 1988). Other forms of disability tend to be anti-male biased. It is possible that this gender phenomenon can be explained by differential (anti-female) mortality. Alternatively, while many

⁹ Causative factors are increases in life expectancy 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.

¹⁰ WHO (1980); Hammerman and Maikowski (1981); Helander (1993).

disabled women may be productively deployed in the domestic sphere, and therefore not socially labelled as disabled, disabled men may be debarred from both wage work or self-employment and domestic work, and thus much more visibly recognizable as disabled. These remain hypotheses. As regards **age**, it is estimated that 6-10 per cent of children in India are born disabled and that, because of low life expectancy, possibly a third of the total disabled population is comprised of children.¹¹ Ocular and aural disabilities occur with ever increasing frequency with age. Where life expectancy increases with wealth in a differentiated society, the paradox of higher frequencies of disability with increasing economic status becomes evident.

Disability and **poverty** are closely related. While disability causes poverty, in a country with mass poverty it is also possible that poverty causes disability (Narsing Rao, 1990). The mechanisms are malnutrition, exposure to disabling disease, inadequate access to inadequate preventative and curative health care, and an enhanced risk of occupation-related accident among the poor. The relationships between poverty (economic disability), “weakness” (social disability) and medicalized disability result in a condition of **simultaneous deprivation**. This is a syndrome composed of ideological reinforcement, punitive experience, psychological extinction (the lack of consequence in behavioural development), stimulus deprivation and a cognitive and verbal development which probabilistically affects the participation of low caste groups.¹² This syndrome sets up barriers to the participation of all types of disabled people — but especially the mentally disabled and especially girls. Some recent research in rural India appears to confirm the positive association. A higher proportion of households with self-reported disabled members were below the poverty line, had total assets below Rs 5,000, smaller land holdings and greater debt than households without disabled members (Harriss-White, 1996).

There are no systematic studies to show how households cope and respond, or the nature and type of social and economic penalties involved in having a disabled member.

Thus the condition of being disabled identifies a big social category, as does poverty. But complexity is central to disability and this medicalized social condition cannot be reduced to one criterion for evaluation in the way that poverty can be appraised and evaluated for policy purposes, however crudely, by income. Just as social factors such as gender, age and caste, and economic factors such as poverty, condition disability, 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 role in the creation and perpetuation of spatial patterns of disabilities (Shukia, 1990).

¹¹ **ActionAid Disability News**, 2(2); Culshaw (1983).

¹² Sen (1992:39-62 and 75-84). On nutrition, which has often been considered a cause of mental and cognitive handicap, Sen concluded that there is no statistically significant association between malnutrition and mental retardation, but that malnutrition is associated with factors such as home environment, the quality of parenting and the intellectual development of the mother, which are statistically associated with mental retardation (Sen, 1992:91-113 and 255). The nutritional relationship between vitamin A deficiency and acquired blindness is, however, incontrovertible (ISS, 1988:15).

Impairment may be ascribed a social stigma and may affect status as a citizen. Mortality may be heightened for social and economic rather than medical reasons. The reasons for disability (disease, congenital causes, accident, war) can and do affect the type and quantum of entitlement. A minute fraction of rural disabled Indians have access to government or NGO programmes. The majority are profoundly socially excluded. The bulk of the non-medical literature on disability is normative and polemical — and concerned with advocacy.

In this paper we have different objectives. First, we aim to show the link between disability and development by means of an analysis of the role of major social institutions for the reproduction of disabilities. These are the household, the community, the market and the state. Then, second, we can turn to the scope for social policy and can challenge both the public choice rationale and the relegation of disability to its pariah state as an unessential and expensive humanitarian issue.

2. THE SOCIAL INSTITUTIONS OF DISABILITY

It is through social institutions that disabilities are produced and reproduced. The key social institution for disabled people is the one about which least has been written: the **household**. That which has been most fully described is the **community**, but “community” nevertheless remains a vague concept. For the anthropologist, it means a society in which face-to-face interaction is normal. In much of the literature consulted for this paper, it means a consensual social unit. That “communities” in the anthropological sense are often riven by faction, ethnicity, class and gender is ignored, as of course are their social consequences. It would seem that this “consensual community” is a concept foisted and projected onto much of the aid-receiving rural world. Community has a third equally vague meaning in the context of developmental organizations. It refers to non-governmental organizations (NGOs) as well as to the set of international donor institutions. In our treatment of community, we shall attempt to avoid this word and to paraphrase the literature more exactly.

The third institution, the **market**, has been defined as an economically qualified, purposeful interchange of commodities on the basis of *quid pro quo* obligations at a mutually agreed rate in a cluster of exchange and rivalry relations (Fourie, 1991). Thus there will be markets for therapeutic equipment and skill training for disabled people, and for goods produced by disabled people. But labour is also a marketed commodity. That rates are “mutually agreed” does not imply that they are entered into voluntarily or with full information and equal bargaining power. Although the market transaction is a one-to-one transfer of property rights, a binary exchange, the process leading to it is one of intense competition, of “rivalry relations” in which disabled people are by definition disadvantaged.

The final major social institution reproducing disability is the **state**. Just as the state is said to have the monopoly over the means of coercion, so it has a monopoly over the means of neglect. We include in our scrutiny of the state

those institutions of government which create the policy agenda, those which create and implement the rules and laws by which the agenda is translated into public action, and those institutions by means of which people (“targets” and “beneficiaries”) gain access to state-allocated resources (Schaffer, 1984).

◆ 2.1 The Household and the Locality

Most disabled people in India live in rural areas and are supposed to be confined to the domestic sphere, and cared for by female kin (mothers and siblings). It is generally assumed that a disabled person’s family provides for basic needs and that disabled people not given special training in childhood are barred from economic participation. There is a serious lack of information, however, about what disabled people do, coupled with anecdotal evidence that income poverty and the increasingly prevalent compulsion of wage work increases the opportunity costs of domestic care and reduces its quality. In this context, a census of self-reported disabled people’s occupations in three south Indian villages produces some challenges to this model of social dependence. While between a fifth and a third of those reporting themselves to be disabled did not work, and although old age and severe disability render adults economically inactive, no type of disability prevented rural people from working. Agrarian poverty seems to compel economic participation and to minimize dependence. A great variety of occupations were reported, including energy and stamina intensive activity such as bullock carting and construction performed by physically impaired people. Agriculture and agricultural wage labour could be performed by those with visual and physical disabilities, while those men and women reporting aural disabilities were most commonly employed in livestock rearing or domestic work. Gender divisions of task did not seem completely inelastic for disabled individuals. Key questions for further research arise from this preliminary evidence.¹³ The first concerns not the fact of gainful activity and domestic work by rural disabled people, but rather the returns from the former and the effectiveness of the latter compared with those of the able bodied. The second concerns the degree of exclusion experienced in remunerated and unremunerated tasks and in social participation. The third concerns the impact of varying severities of disability (experienced as unrelated to the clinical or legal thresholds for entitlement which have no reach in villages) on the social and economic support needed inside and outside the household.

While low self-esteem and conventions of passivity on the part of disabled individuals may hamper their social participation and reinforce their isolation, the social attitudes of the non-disabled are also known to affect the social integration of disabled people. “The more severe and visible the deformity is, the greater is the fear of contagion, hence the attitude of aversion and segregation towards the crippled” (Desai, 1990:19). Ignorance of needs and capabilities may hinder social relationships. Disabled people may be feared as evil, cursed or spiritually afflicted (Coleridge, 1993:71; Miles, 1995). Additionally or alternatively, they may be over-protected.

¹³ Raw data from the Queen Elizabeth House/Madras Institute of Development Studies village censuses in Tiruvannamalai-Sambuvaraiyar District of Tamil Nadu, 1993.

They may be segregated as contagious, particularly those afflicted with leprosy (Coleridge, 1993:71).¹⁴

Attitudes reinforced by religious institutions may militate against rehabilitation or integration, although the great religious traditions may contain contradiction. Treatment and training may be understood as defiance to the will of Allah or as interference with a person's karma. While alms-giving to beggars is pious behaviour, "Hindu religious organizations and temple trusts, many of them very wealthy indeed, do not think it part of their duties to help the handicapped, as they consider the handicap to be the result of the victim's misdeeds in his previous life" (Narsing Rao, 1990:154; see also ISS, 1988:37 and 67; Coleridge, 1993:17 and 152-154; Miles, 1983; 1995).

◆ 2.2 Missionary and Religious Organizations

The conventional rehabilitative institutions had their origin in the poor laws and workhouses of imperial Britain (Barnes, 1991). Schools and sheltered organizations providing education, food and some vocational training for the blind and deaf established and run by (foreign) missionaries have been part of the Indian education system since the 1820s (Narasimhan and Mukherjee, 1986) and the model of segregated institutions is widely replicated.

There are many more private religious institutions for disabled people than there are government institutions. They are dominated by Christian organizations. Many Indian NGOs established post-independence on a comparatively large scale are still funded by Christian organizations abroad. The direct involvement of foreign Christian missionaries is now extremely limited to a small number of expatriate Christian professionals.

Disabled people are also rehabilitated in the institutions of other religious groups, notably Parsees and Jains. The dominant Hindu religion contributes individuals but (with the exception of the Rama Krishna Missions and Seva-in Action of reformist sects) no organizations.

According to the ISS report on the handicapped in India, religious organizations may recruit from their own religion but by law must not and generally do not discriminate by religion in the services they provide. These institutions generally also find composite sources of funding from government, business houses and individual philanthropists. But funds and sources tend to fluctuate unpredictably and there is little public support. Segregation in "institutions" was seen by the ISS research team as inevitable for disabled people abandoned by their families, particularly for severely mentally retarded people, and fairly inevitable for disabled people of rural origin who had been (re)habilitated in urban locations. Religious organizations were found to be "more urban" than government institutions. Finally, the state was found to be unable to regulate religious institutions (as well as other non-religious NGOs) (1988:37-61).

¹⁴ With respect to leprosy, for instance, while 30 per cent are deformed, only 20 per cent are infectious, but this fifth turns victims of leprosy into social untouchables (ISS, 1988:19).

Segregated institutions were originally justified, if at all, in terms of the social support derived from the existence of specialized facilities for therapy, training and adaptation, a non-stigmatizing social environment, economies of scale and the provision of relief to able bodied carers and over-burdened teachers in regular schools. But by removing responsibility for a disabled person from the family and the community, the family learns to live without the disabled person and to take over any role or tasks they might have performed. This reduces the chances for disabled persons themselves to learn to cope with their normal, usually rural, environment both in a cultural and in a practical sense (WHO, 1981).

Segregated institutions have been criticized for patriarchal and male supremacist administrative cultures, for abuses of social control (a response to their own scarcity?) and for denial of human rights. They are also now seen by movements of disabled people as denying (rather than providing) opportunities to disabled inmates and as imposing a different stigma on those who leave (Coleridge, 1993). Such stark, binary oppositions are unhelpful. For certain types of disability, segregated institutions may be the only practically feasible response.

◆ 2.3 Other Non-Governmental Organizations

Modern NGOs (some of which are global in organization) have two focuses: physical welfare and integration through social relations. The development of services for different types of disability has been uneven. Visual disability and deafness are the aristocrats and orthopaedic disability and mental retardation the underlings. There is a large literature detailing NGO activities which shows (but rarely evaluates) the scope of their response. The blind are most comprehensively provided for — for example, eye hospitals, corrective surgery and clinical care, mobile clinics, agricultural and other types of training (including computing). For the physically disabled, including lepers, NGOs can and do provide corrective surgery, in-home rehabilitation, physiotherapy, occupational therapy and training, prosthetics provision and production, preventive vaccination (e.g. for polio), loans and job placement, and specialized housing. The best NGOs not only provide rehabilitation for wage earning but also for domestic tasks (Culshaw, 1983; Jackson, 1988).

NGOs are not always local or grounded in “communities” (even where communities exist). More often than not, they combine local people with outside professionals. Furthermore, NGOs and the state are also locked in an institutional embrace, not simply the product of minimalist regulation by registration but more directly through finance and through capture and substitution. This relationship works in a variety of ways. For example, philanthropic business organizations release the state from cataract removal operations; and the National Association for Equal Opportunities for the Handicapped (established in 1969 for relief and rehabilitation across a range of disabilities) and the National Council of Churches in India (established in 1947) have representation on government policy forming bodies.

Such institutions, both voluntary and (partly or wholly) government funded, are numerous enough to prevent federation and yet wholly inadequate to the need: for the blind, 265; for the orthopaedically handicapped, 200; for the deaf, 190; for the mentally retarded, 116; and for lepers, 247. Developments

over the past decade have gone some way to rectify the imbalance visible in the mid-1960s between relatively numerous organizations for the blind and sparse organizations for the mentally retarded. In the embrace with the state, charities are tantamount to voluntary agents of government — they are thus hardly **non-governmental** organizations.

A society relying on NGOs as the mechanism outside the household for the delivery of social welfare accepts their insecurity of funding and their social costliness. Such a society accepts the minimal regulation of NGOs' service provision and their sometimes quirky allocative priorities. Unco-ordinated technology transfer has resulted in four separate systems of sign language for the deaf and at least twelve kinds of Braille being promulgated in India. Such a society also accepts their unstandardized scales of remuneration. It is common to find the co-existence of highly remunerated professionals with volunteers. This commercialization of the voluntary sector blurs the distinction between private services based on effective demand and public services based on social rights. Where NGOs have rights to tax relief, this exemption is ultimately paid for by tax payers. Charitable social welfare provision is on a very small scale — need cannot be responded to systematically by provision. The “projects” brought by NGOs conventionally socialize disabled people so as to desocialize them from their natal social unit. Access is in essence on discretion. Disabled clients are forced by lack of alternatives into a fragile dependence on institutions, often relying on the motivation and competence of a single individual. Redress for incompetence is practically impossible to obtain. The information and transactions costs of access to competent professionals are high, as are the psychological costs of the self-abasement required to prove oneself worthy of charity (Culshaw, 1983:84; Helander, 1993; Coleridge, 1993; D.G. White, personal communication, 1990-1995).

◆ 2.4 Markets

Arguments in favour of the market provision of protective therapy are couched in terms of a state alternative rather than a charitable one (or both). They run along the following lines. Faced with a free good, “public demand” (in this case from disabled people) is extended until its marginal utility approaches zero. Under a tax-financed system of therapy, however, there will be under-supply. Such features of demand and supply will lead to shortages, poor quality services and long queues. This is indeed what happens commonly in India with regard to every aspect of the public health system. It is therefore argued that markets should handle resource allocation, and that the state should confine its attention to issues of income distribution.¹⁵

It is also reported that “the poor” prefer private to public health therapy and that private institutions are better run (ISS, 1988:37).

2.4.1 Markets for equipment

Little information has been discovered. The local capacity to manufacture and market therapeutic equipment for disabled people is a plus for

¹⁵ In this context, vouchers are proposed for access to health services for the poor and disabled.

appropriate customization, and for low capital and maintenance costs. Imports are more often than not inappropriate for one of these reasons (Miles, 1989a). Some NGOs produce prosthetics and the parastatal ALIMCO has, since 1979, exported prosthetics to the Far East, and South-East and South-West Asia. Market access to what the ISS report termed “the best medical therapy” and to rehabilitation in private “homes”, institutions and hospitals is, of course, structured by ability to pay and thus accessible only to the rich (ISS, 1988:63).

2.4.2 Markets for skill acquisition

Worldwide there are many consultancy organizations which execute infrastructural projects and recruit personnel (sometimes internationally) for promotively therapeutic employment, such as occupational and vocational training for the future paid employment of disabled people. These organizations do not have an interest in the cost-effectiveness of the programmes in question (Helander, 1993:61). Such commercial services are confined to wealthy urban individuals and institutions (Miles, 1990). In rural areas we find a paradox of disability, in that the trained and rehabilitated individual is too skilled for the available employment opportunities in villages. As the ISS report neatly puts it: “he [sic] is turned into a sort of ‘élite’ handicapped” (1988:40). Or “he” may be equipped with obsolete skills for which there is no market.

2.4.3 Sheltered employment

In competitive markets, the private provision of adapted workplaces may raise costs of production and put firms at a competitive disadvantage. The intense segmentation of markets in India offers the possibility of productive work for a minute proportion of disabled people in firms specialized in their employment. These “sheltered conditions” differ from those of segregated institutions — though they may elide with them — in allowing the possibility for some of residence at home. Prosthetics production, educational toys, specialized equipment for the disabled, a power laundry, silk screen printing, tailoring, snack bar management, carpentry, metal work, leather craft, candle and chalk making, horticulture, livestock, printing and publishing, music and massage all operate under such conditions in India. A few comments are in order. First, sheltered employment needs to be appropriate to specific, or a specific range of, disabilities. Second, skills such as computing, light engineering and electrical engineering are most marketable. Third, for some enterprises rates of return to capital invested are commercially respectable (e.g. orthopaedic appliance manufacturing, 5 per cent; press, 15-20 per cent; toys, 15 per cent; power laundry, 25-30 per cent).

2.4.4 Formal sector labour markets

In India a paradox of disability is that a disabled person must be highly qualified to enter the formal labour market (ISS, 1988:40). Disabled people are thought to provide a docile reliable and obedient workforce, assumptions used as justification for the skilling of disabled people (Ewing, 1991:9) and echoing similar arguments for the factory employment of women (Pearson, 1988).

Disabled people, however (rather like women in general), experience labour markets both structured against them (via the architectural environment, lack of latrines, etc.) and discriminating against them on many grounds:

- productivity;
- threat to workplace safety;
- the cost of site design;
- their unreliability;
- the impact of preferential treatment on other workers.

These grounds have been debunked (Helander, 1993). There is no evidence of lower productivity where disabled people have been appropriately placed. Moreover, disabled people have a lower turnover. Workplace accidents have been found to be associated with job related hazards and not with the presence of a disabled worker.¹⁶ The cost of redesign of built work sites can be low. Disabled people are negligibly more unreliable. A disabled wage worker loses 3.8 days/100 compared with an able bodied worker's 3.4 days, a difference which is not statistically significant. Preferential treatment is a general problem of targeting and more often found in the state sector than in open labour markets. The problem for targeting is that its justification is obscure to people deprived in other ways.

2.4.5 Beggary

Begging has been an important source of subsistence for disabled people and their families (Mallory, 1993). There are known to be over 200,000 beggars in India with leprosy (ISS, 1988:19) but no study of disabled beggars was located for India in our bibliographical search. Research on disabled Kenyan beggars revealed that 94 per cent resorted to begging having failed to obtain wage work. It was concluded that "begging is relatively lucrative for people with disabilities, compared to the average wages earned by other disabled people. Typically, disabled beggars earned from 50 to 100 per cent more than their non-begging disabled peers (Mallory, 1993:20). However the disabled beggar is also thought to be vulnerable to exploitation by criminals and racketeers; children may be deliberately maimed and located at religious places and busy thoroughfares to exploit "the alms giving sentiment" (Miles, 1983:6 and 70; ISS, 1988:40 and 65).

◆ 2.5 The State

The unique contribution of the English language to the study of policy is the distinction between a neutral concept of "policy" — those actions of the state — on the one hand, and "politics" — those relations of power giving rise to such actions. This distinction is not allowed in other languages and will be disputed in this section, which takes a political approach to the institutions of policy. There are three political processes comprising public action. These are the politics comprising agenda formation; those surrounding law, procedure and adjudication; and those surrounding resource mobilization, allocation and access.

¹⁶ In Western studies.

These will be examined in turn. However, prior to such an analysis must come one other into the terms of discourse on disability and development. Discourse — the language deployed for analysis of the policy process — reflects the sometimes competing interests of the social institutions demanding that very discourse. It is the product of power relations.

2.5.1 The terms of policy discourse

A central issue in any policy debate on disability concerns the rationing of resources to disabled people within a system of public sector care. Public care competes for resources with other institutional contributors to the social and political order,¹⁷ and *ab initio* convincing justifications that the social health of disabled people is a necessary precondition not only for economic growth but also for social welfare have to be provided.

Resources for disabled people need to be distributed across a range of government departments. This means that from the outset this meta-label is an item administratively marginalized and segmented. And yet labelling, categorizing and prioritizing is a necessary administrative activity, given conditions of scarce resources where demand outstrips supply. Existing empirical evidence suggests that within each department if criteria are systematically used for rationing, they will a) be highly culturally specific and varied and b) place the needs of disabled people low in an ordering of priorities.¹⁸ The criterion most commonly deployed in public sector allocation is that most difficult to defend on ethical grounds — ability to pay.

Given conditions where it is impossible to redistribute from individuals according to their income to individuals according to their need, more equitable distributions of resources have to be justified in terms of cost-benefit and cost effectiveness accepting the social specificity of research, development and technology.

There are special problems in the application of cost-benefit and cost effectiveness analysis to disabled people. The productive capabilities of disabled people have never been evaluated in isolation from some intervention intended to increase these capabilities. Such exercises give rise to agency problems common to many public health and nutrition investments in computing the monetary value of income or benefit attributable to a given intervention. It is also almost impossible to measure human and social benefits (thereby under-valuing projects) or economic benefits to people in non-working age groups or to people whose work is unvalorized. As a result of such technical problems, projects for disabled

¹⁷ Such as defence, science and culture, and social institutions such as the family (Callaghan, 1987).

¹⁸ The Seattle study of social worth as a rationing criterion revealed the following priorities: married men with children before unmarried men and all women; employed before unemployed; church-goers and community-minded volunteers before others. Social deviants and the mentally disabled were rejected out of hand (Sanders and Dukeminier, 1969). Another rationing study found the youngest prioritized above older people; those faced with imminent death prioritized high; people most prominent in achievement; those claiming special responsibilities; wealth (high) and nationality (local) as meriting priority (Menzel, 1991).

people can be evaluated in terms of social cost effectiveness, but only where more than one institutional means of attempting a given outcome objective is available for comparative purposes.

Costs are complex and many are difficult to assign value to. They accrue to a variety of social institutions. The costs of disability comprise the routine capital and depreciation costs of buildings and equipment for surgical, clinical and psychological treatment, for schooling or training, occupational therapy, transport (borne by institutions of therapeutic provisioning), direct costs to the individual or their family (of healers, of technical equipment and medicine, of wear and tear),¹⁹ the direct, opportunity costs of care, the indirect long term costs of current and future income foregone by the “carer(s)” and transfer payments (pensions and other welfare benefits with their associated administration costs (born by the state on behalf of society). In addition, discount rates have to be computed to bring future costs back to present values, rates which need to be specific to age, gender and social environment.

Benefits of rehabilitation can be evaluated both in terms of income generated and reductions to the cost of social insurance and assistance. Benefits include reductions in the future costs of care for the disabled, direct returns to productive activity of the disabled person or the carer, and reductions in transfer payments and their administrative costs. But when social welfare is confined to employees in the organized sector, as in India (Guhan, 1992), while disability is overwhelmingly found in sectors without access either to organized sector employment or to public sector social insurance or assistance, the difference between financial and social accounting is likely to be considerable. Helander, for instance, computes the social cost of domestic support for all moderately and severely disabled people based on the opportunity cost of full time support being equal to per capita GNP for a scenario representing an industrialized country at 8.4 per cent of GDP (Helander, 1993:206-209) while because of the under- or non-valuation of female labour the financial cost will actually be much lower.

Such technocratized policy discourse is actually the product of a set of values expressing a polity where economic productivity, measurable or imputable in money terms, is positioned in first place as a criterion for allocation. This apparently depoliticized discourse is not the monopoly of state, but is also held by the United Nations (which may have been its epicentre) and is increasingly used by NGOs (whose charitable ethics are under pressure from commercial ethics), and is becoming the institutional lingua franca.

2.5.2 The agenda

To have a formulated disability policy is a recent notion (Miles, 1989a:111).

The policy agenda is, and long has been, formed by forces other than that of the now hegemonic policy discourse of administrators: by the media, by professional and business interests, religious orders, academics, politicians

¹⁹ Western evidence suggests that this component alone adds 35 per cent to the living costs of the severely disabled (*Guardian*, 29 March 1995)

and institutions of civil society (UNICEF, 1994). A historical approach is useful to understand current conditions.

By the 1860s the colonial government endorsed asylums and “sheltered homes” for “destitutes, beggars, and the handicapped”.²⁰ The Freedom Struggle and parallel movements for social reform led to conditions conducive to the multiplication of private (charitable) institutions which the post-independence state either took over or registered. The post-colonial project of the Indian central government did involve the creation of a welfare state, but the institution to preside over this, the Planning Commission, does not have a constitutional status and many of the interventions required were under the jurisdiction not of the central government but of the states.

During the first three Five Year Plans (1955-1969) the sole support to the disabled comprised grants in aid to NGOs and the establishment of national training institutes (see below).²¹ Table 2 shows how support for the disabled declined in real terms as social development priorities, programmes and projects emerged.

²⁰ In the “native states” such services were also developed (M. Miles, personal communication, 1994).

²¹ Of the total social welfare budget during that period, Rs 247.3 million for the Central Government and 119.5 million for the states, Rs 12 million went to rehabilitation, Rs 25 million to welfare support for the handicapped and Rs 10 million to support NGOs (ISS, 1988:23).

Table 2
Plan Allocations for Disabled People (Rs million)

| | 4th Plan 1969-1974 | 5th Plan 1974-1978 | 6th Plan 1979-1983 | 7th Plan 1985-1990 |
|-----------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|
| Welfare of disabled people | 37.5 | 134 | 240 | 250 |
| Grants to NGOs | 60 | 111 | 185 | 210 |

Source: ISS, 1988:26

Under the most recent 7th and 8th Plans, prevention has been stressed and the full panoply of anti-poverty policy claimed as relevant to disabled people. National preventative programmes, and district vocational rehabilitation centres have been planned and instituted. The Ministry of Social Welfare, which is responsible for disabled people, has three current official objectives: i) prevention, ii) training, and iii) development of services (Thomas, 1990).

International institutions have long played a (limited) role in domestic policy formation. As early as 1925, the International Labour Organization (ILO) expressed concern over the vocational needs of disabled people and officially recommended in 1952 that employers and workers maximize the opportunities for disabled people to perform, secure and retain suitable employment.

The International Years of the Child (1979) and the Disabled Person (1981) helped bring publicity to the plight of disabled persons, expanding awareness about disability's being a widespread but largely preventable or remediable social problem and stressing that attitudinal barriers were among the most disabling factors, but they did little to improve public policy (Miles, 1989b:3-4).

2.5.3 Procedure

Historically, the Indian constitution offers no comprehensive or specific legislation ensuring the rights of the disabled Indian (Bajpai, 1991). In India disabled people are given concessions in two sectors of the economy: **education** and **employment**. The legal justification for such reservation is beyond controversy, however there is no direct provision in the constitution conferring on disabled people a legal entitlement to such reservation. Disabled people's "rights" are instead protected by a class of administrative procedures called the Office Memorandum, which has no significance in law.

The constitutional entitlement of disabled people has to be derived indirectly from other legal labels which may be applied to such citizens: for example Article 15(3) enables the state to make special provision for women and children; Article 15(4) for socially and educationally backward classes of citizens, for scheduled castes and scheduled tribes; Article 16(4) allows the state to make provision for the reservation of appointments or posts in favour of any backward class of citizens which in the opinion of the state is not adequately represented in the service of the state. But the condition of disability cuts across gender, age, class and caste and there is no specific provision requiring the state to provide for disabled people.

Another possible constitutional buttress for the practice of employment reservation for disabled people appears to be the “equality clause” under Article 14. This article ensures equal opportunity for all persons before the law and equal protection of the laws. It is quite obvious that “equal opportunity” and “equal protection” can only be between those who are equally situated. It is also obvious that treating unequals as equals will only result in injustice. So, although there is no specific provision in the constitution for reservations for the disabled, such reservation is legally justified on grounds that they are not equals with non-disabled people.

Article 41 is the only article explicitly to mention disabled people. But it appears under Part IV of the Indian Constitution which concerns “Directive Principles of State Policy”. Unlike fundamental rights, these directive principles are not directly enforceable through the courts even though they are “fundamental in the governance of the country” (Article 37) and even though it shall be the duty of the state to apply these principles in making laws. Thus Article 41 reads:

The state shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want.

The development of procedure to reserve employment for disabled people has been slow and piecemeal, lagging far behind that for scheduled castes and tribes. From 1957-1965 a “sympathetic attitude” to disabled people was encouraged by government order. Employment concessions were introduced in 1965, reservations in the lower levels of central government service and in public sector enterprises from 1977-1978 and discretionary “preference” in upper levels in 1986. Promotion between the lowest two groups in government service had to wait until 1989 (Ram and Harriss-White, 1995).

The general weakness of state support to the disabled is also exemplified by the colonial Indian Lunacy Act of 1912, established to protect **mentally retarded and mentally ill people**. The act allowed that any mentally retarded adult could be consigned to an asylum by familial request or through official certification by a doctor, psychiatrist or magistrate. Any wandering or destitute person could be deemed of unsound mind and relegated to an asylum by a magistrate, as could a convict who had become violent in prison (Culshaw, 1983). It was not until 1975 that the Lunacy Act was superseded by the Mental Health Act, which attempts to differentiate between the needs of the mentally retarded and the mentally ill. According to the act, a mentally ill person is one in need of treatment by reasons of any mental disorder other than mental retardation. Mentally retarded persons were thus released from the protection of the state and classified henceforth with other disabled people and covered by loose legal provision.

In addition, there exist various acts which are intended to provide legal mechanisms by which the disabled Indian is protected from **discrimination and certain kinds of liability**. The Indian Contract Act of 1872 absolved any person of unsound mind from contractual liability. Severely mentally retarded Indians are considered “not legally competent to contract for want of general comprehension although some may be educable to a limited

extent” (Tilak, 1991:26). Historically in both Hindu and Muslim law, the marriage contract was absolvable on account of mental instability in a partner. Under Islamic law, a mentally retarded person was considered to be a minor and in Christian tradition, a lunatic or idiot could not marry. Section 5(1) of the Hindu Marriage Act of 1955, and Section 4 of the Special Marriage Act of 1954 state that marriage is not legal either if one party experiences “mental suffering” and is thereby unfit for marriage or procreation, or if a party is subject to insanity or epilepsy. Section 7 of the Hindu Adoption and Maintenance Act of 1956 prohibits a person from adopting a child unless the adopter is of majority age and of sound mind. The qualifications for soundness of mind eliminate those with epilepsy, mental illness or retardation. Since Section 9 of this act states that parents and guardians of children alone can give children into adoption, a mentally ill parent does not have to renounce their child but a mentally ill adoptive parent is not allowed to adopt. The only act appearing to accord the disabled person positive rights of entitlements is Section 28 of the Hindu Succession Act of 1956, which prevents disqualification from succession to property on the grounds of any disease, defect or deformity.

With the exception of this last act (which indicates the importance of family property for the resource base of disabled people) the net effect of these acts is to limit the freedoms accorded to disabled people rather than serving to empower them.

The international legal rights of disabled people have only recently been articulated. In 1975 the United Nations General Assembly established that disabled and able bodied people should be accorded similar rights, opportunities and respect. Also in 1975, the United Nations Declaration on the Rights of the Mentally Retarded Person provided legal safeguards against abuse, and the United Nations Declaration of the Rights of Deaf-Blind Persons was guaranteed by the Universal Declaration of Human Rights.

But rights without mechanisms to claim and without obligation to provide are empty (Alston, 1994). The social value of the national and international law concerning disabled people is, as is the case for bonded and child labour, largely symbolic. It exists as an unreachd goal for political mobilization to support the legal concerns of the disabled population and to promote their rights to engage in economic activities.

Procedural aspects of policy for disabled people suffer from being low status, arbitrary and the result of a reactive politics. The mandate of the state under Article 41 of the Indian constitution envisages a comprehensive social security system which enables the lives of disabled people to be fulfilled. This constitutional responsibility is currently realized only in a weak reservations policy. It is an insultingly callous political response. Moreover, mere provision in the form of discretionary office memoranda does not guarantee entitlement. According to the Supreme Court, which has the power to set binding precedents through judgements, “it is not possible to compel the state through the judicial process to make provision by statutory

enactments or executive fiat for assuring the basic essentials which go to make up a life of human dignity”²².

The rights of disabled Indians are not guaranteed in law. But historically, citizenship rights have preceded state obligations for socio-economic welfare. The social value of the international law concerning disabled people is, as is the case for bonded and child labour (Dhagamwar, 1992), more than symbolic. It provides a normative leverage for advocacy.

2.5.4 Access

The needs of the disabled are compartmentalized under the Ministry of Social Welfare. The latest data on resources show that this ministry allocated the sum of Rs 960 lakhs for disability related programmes in 1988-1989. This sum is less than the budget for a medium sized municipality. It is less than the short term co-operative credit for a small district. It is less than what neighbouring Sri Lanka spends on disability in a population under 2 per cent of that of India's (Badrinath, 1994)

These small funds are used for four national training institutes, for the subsidized production and distribution of prosthetics and for some financial assistance to an estimated 35 per cent of the voluntary agencies mandated to assist disabled people — an estimated 200 per year. The Ministry of Social Welfare will subsidize up to 90 per cent of a qualifying organization's budget for prevention, specialized vocational therapy, training, therapy, placement, buildings and equipment. The four training institutes are run by the Ministry of Social Welfare and produce specialized health care professionals, educational materials and research on rehabilitation strategies. In principle, the state finances, on a means-tested basis, the purchase of artificial limbs (both orthopaedic and prosthetic) for physically disabled people, the purchase of Braille kits and tape recorders for blind people, and corner seats and prone boards for spastics (Culshaw, 1983). As of 1990, access to 100 per cent subsidies on goods and services up to Rs 3,600 required a monthly income below Rs 1,200 and access to 50 per cent subsidies was limited to those with monthly incomes between Rs 1,201 and 2,500. In practice these funds are severely rationed, both to voluntary agencies and to individuals.

Access to state services is also extremely limited. As of January 1989, the National Institute of Mental Health funded 450 institutions providing services to 18,000 mentally retarded people out of the estimated maximum of 4 million eligible; 30,000 mentally disabled children (under 1 per cent of the “eligible”) are catered for in some way by this system. On aggregate, 0.6 per cent of disabled children, less than 3 per cent of the total of physically disabled and under 1 per cent of the total of mentally disabled, are estimated to have access to rehabilitation services of the state or of voluntary agencies (Coleridge, 1993:22 and 47; Narayan, 1990; Sen, 1992:25). While it may be argued that people with disabilities use “ordinary” state services, the National Sample Survey reported that over half the disabled people they identified had **never** seen a qualified physician for any purpose (in Sen, 1992:63).

²² In the case of Bandhu Mukji Morcha (Ram and Harriss-White, 1995:40).

As with NGOs, the evolution of specialized state services for disabled people has been biased both in terms of types of disability and in social terms. Eligibility in some states does differ from those criteria used for labour market participation (wealth and urban location) and those criteria sometimes alleged to be used for screening by NGOs (family wealth). Many state institutions evaluated by the ISS were concluded **not** to be screening actively by caste or wealth. However, when it came to general conclusions, “scholarships were not given to illiterate disabled people” and access to government institutions was filtered by a family’s capacity to bear delay and the costs of charges to intermediaries and bribes to officials (ISS, 1988:66).

The inevitable impact of state under-funding on such a scale, and of the dispersed and joint responsibilities of state and a variety of NGOs with limited, self-defined briefs (lobbying, philanthropic-finance, medical services) has been made public in a series of case studies of the human rights abuses accompanying the arbitrary sterilization of mentally retarded girls committed by courts to a segregated institution in Maharashtra. These include inadequate, under-trained and under-remunerated staffing, water shortages, under-feeding and unsanitary conditions, sexual harassment and the recourse to arbitrary and technically illegal surgical interventions as technical solutions to social problems (Bidwai, 1994). The ISS lists “rampant corruption, lack of drugs, diversion of funds, pilferage of food” as common institutional pathologies (1988:29).

In such cases, human rights abuses form a nexus with corruption, under-funding and severe institutional scarcities. In setting its current welfare priorities the state has abdicated its responsibility for disabled people (albeit a weak responsibility under the constitution) and is currently unwilling to substitute for the market or the various institutions comprising the “community”.

Formal sector **reservation** is not guaranteed by the Indian constitution but 1 per cent of C and D category public sector employment (clerk, assistant, orderly, peon) is allotted to blind, deaf and locomotor disabled people. While most states strain to comply with this reservation, in Tamil Nadu state, this quota is as much as 3 per cent and there is also a 3 per cent quota in all professional and technical institutions.

In the public sector there are 22 special employment exchanges located in urban areas. The only evidence to hand about their impact is dated. According to a report of the Ministry of Labour, at the end of 1983, of the 151,400 physically handicapped using these special employment exchanges 6,400 — or 4.2 per cent — had been placed, which was insignificant in relation to the total disabled population of the country as a whole.

No evaluation of the system of reservations for disabled people has been found. It is said that reservations are not monitored and that quotas are not filled. In such conditions, the practice of reservations, and concessions for disabled people, is putting the cart before the horse since there is no congruence between resources and the population eligible for them. It is also argued, usually by non-beneficiaries, that rather than reducing disadvantage,

such positive discrimination reinforces it by the intensely political focus given to labelling and eligibility.

So far, the Indian state has therefore failed to create a coherent agenda for disabled people, a legal frame of obligation and an institutional means whereby needs can be translated into practical claims. The resources devoted to alleviating disabilities, to which a tiny fraction of those needing support actually gain access, are on a trend of decline in real terms. The state also fails to regulate both the private sector and NGOs with any consistency. For the mass of disabled people, the state does not exist.

3. SOCIAL POLICY OPTIONS FOR DISABLED INDIANS

India is undergoing an era of stabilization and structural adjustment. New social policies for disabled people are in danger of strangulation at birth, both from the fiscal and social expenditure reforms characteristic of such liberalization and from state compression. In theory inter- and intra-sectoral public expenditure choices should be made so as to equalize the marginal rates of return, weighted by the share of benefits received by the deprived population.²³ In theory targeting corrects inequitable primary income distributions by the fine tuned transfer of resources. In theory, the protection of welfare expenditure can have counter-cyclical effects on the welfare, efficiency and productivity of deprived people during periods of structural adjustment (Blejer and Chu, 1990).

But in practice, it has been found that in countries where the growth rate of public expenditure is declining, the intersectoral shares of public expenditure adjust in such a way that interest payments rise at the expense of social expenditure and economic services. Intra-sectorally, adverse shifts in both welfare and efficiency tend to occur²⁴ and there is no trigger to redistribute resources to subsectors with the highest rates of return. Targeting is not easy to fine tune and welfare subsidies needed for targeting are withdrawn (Pinstrup-Andersen et al., 1987). Finally, indirect taxation (which is often socially regressive) increases while direct taxation is reduced (Cornia and Stewart, 1990:27-33).

While policy advocacy is couched in depoliticized language, policy practice blatantly disobeys this reasoned advocacy, performing according to different, politicized principles. Ironically, while technical advocacy creates room for manoeuvre for investments in disabled people even under conditions of structural adjustment, the practice of policy squashes this political space.

²³ Social rates of return have been demonstrated to be highest for education, training, rural infrastructure and health. Sectoral distributions with maximum positive impact on the poor are social services and transport (Alailima, 1984).

²⁴ For instance tertiary health and educational facilities are protected at the expense of primary services (Cornia and Stewart, 1990).

If only for reasons of electoral expediency, India's adjustment experience is the exception to prove these rules. While liberalization proceeds apace, attempts are made to protect anti-poverty policy, and social assistance and insurance in individual states (Olsen, 1995) as well as at the Centre (Singh, 1995). Disability is conspicuous by its absence in the latest budget. What kinds of policy options are evolving for this reformist phase of India's development?

◆ 3.1 Community Based Rehabilitation

First set out by the World Health Organisation in 1969, Community Based Rehabilitation (CBR) involves "the combined and co-ordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest level of functional activity" (as quoted in Helander, 1993:15). The concept is continually evolving. To the original decentralized intervention has been added recognition of the presence of physical barriers in the environment, and much later, at the instigation of disabled people themselves in the Disabled People's International of 1981, "equalisation of opportunities... — the removal of barriers to the full participation of disabled people" (as quoted in Helander, 1993:16).²⁵

CBR is a reaction. It has risen, phoenix-like, from the ashes of rejected segregated institutional care (Miles, 1990). It is a response to the failure of states and NGOs to meet needs in the light of abundant evidence of the imbalance between requirements for training and rehabilitation, and the resources available.

CBR has six goals: i) to deinstitutionalize medical care; ii) to expand access to rehabilitation; iii) to "demedicalize" social responses to disability and contribute thereby to a reduction in social stigma; iv) to work with disabled people *in situ* and not in segregated institutions; v) to reduce the cost of appropriate service provision and vi) to shift investment from curative to preventative measures (Narayan, 1990; Thomas 1993b)

The concept is institutionally flexible and could be operationalized by "communities", NGOs and by government. Local level identification, training and technology development is encouraged, involving not only disabled people and their families but teachers, healers and religious leaders. This is not to substitute cheap alternatives for specialist professionals but to promote a different social system for therapy and integration (Helander, 1993:87-173).²⁶

No systematic quantitative economic data on outreach or cost effectiveness have ever been marshalled. Evaluations have been concerned with the definition and measurement of achievement in relation to types of CBR

²⁵ These barriers are found in the physical environment, in housing and transportation, social and health services, educational and work opportunities, cultural and social life including sports and recreational facilities.

²⁶ Miles (1989b, 1990, 1993) has proposed information-based rehabilitation. At present, cost, engineering, maintenance and language difficulties are likely to make a computer-based reconceptualization of CBR unlikely to be feasible, though the principle has been put into practice in primary health care.

inputs and the initial severities of disability; and have been non-comparative. A review of six careful, non-economic evaluations employing baseline and follow-up surveys in a set of countries shows an association between CBR and a reduction of disability in 80 per cent of cases, as a result of which CBR is considered “highly effective” (Helander, 1993:175-183).

In India, the shift from professional, institutional carers to non-professionals has been exemplary (Murthy, 1991). More widespread awareness of (re)habilitative potential resulting from existing CBR induces positive feedback in resource allocations by NGOs and thence to government. Partly as a result, in 1985 the Ministry of Social Welfare launched a District Vocational Rehabilitation Centre scheme piloted in 10 districts, with the aim of bringing appropriate services to much larger numbers of disabled people than hitherto attempted. That the scheme is decentralized does not mean that it is rural. It is still in a pilot stage and has received no independent evaluation.

The case against CBR may be the case against misapplications of CBR — but then CBR may be a utopian policy. The very notion of rehabilitation assumes that disability originates in trauma or disease and leads to the neglect of congenital disability manifest at birth. CBR has been criticized as trapped by being designed for existing institutions, i.e., Western NGOs with concepts, personnel, agendas, technology heavily influenced by practice in developed countries and suffering information-technological and institutional inertia. Advanced information-technological skills and computer aided design potentially customisable at the local level face resource constraints, just as CBR faces difficulties of physical access to remote locations. Education and equipment do not necessarily empower, especially in conditions of insecure funding. There are real resource constraints in the further deployment of labour in assetless families for the care of disabled members (Coleridge, 1993; Helander, 1993; Jackson, 1988). The special privileges required for equal economic status are resented and often usurped by those enduring other types of deprivation as well as by the non-deprived.

With regard to institutional engineering, different disabilities are at different stages. Mentally retarded people are still “untreated” or segregated while blind people are most easily integrated and in the vanguard of new social movements rising from the criticism of CBR and continued state and social neglect.

◆ 3.2 Challenging Public Choice

Internationally, in a context of scarce public resources, concern with economic efficiency and collective social well-being are replacing concern with individual rights and are requiring their sacrifice. As yet, India has no coherent disability policy and no argued basis for alternatives to the present conditions of extraordinary state neglect resulting (at its most simple) from a calculus of efficiency which has been exposed here as seriously limited and misguided. Yet the very expression of such issues can be argued to be a destructive capitulation to the agenda and methodology of public choice theorists, and to policy based on efficiency criteria, because even a tentative answer accepts a discourse which devalues whole categories of people.

We have argued here that disability is a development issue. But how to change in practical rather than exhortatory terms the depressing political calculations manifest from this account? To back disability is to back a historic loser. Two responses suggest themselves: collective action by a variety of interests, and renewed justifications for developmental action by the state. There are practically no systematic data from India with which to buttress our discussion of these responses.

3.2.1 Social movements of collective action

Two types of interest may provoke collective action. The first, ironically, is **élite self-interest**. Although the élite can purchase care and usurp non-market provision, such that the private costs of disability are not a political issue for this class, the élite cannot prevent the increasing incidence of disabilities (due to old age, survival of disease or trauma) concentrated in this class of resource controllers through the inexorable march of the demographic and epidemiological transitions. “Disability is an issue that touches us all. It .. can affect anybody of any background in any country at any time” (Coleridge, 1993:6).

The second type of political interest is in the process of generating a different kind of social movement and involves **reversing the political weakness of disabled people**. By its very nature, disability cannot be a class-based issue but it can be a pressure group throughout society, though the difficulties of making common cause around disability between castes, religions and languages need no exaggeration. There are at least three institutional mechanisms by which disabled people may be empowered in an underdeveloped state such as India. The most significant seems to be donor pressure on states, perhaps through the conditionality clauses on transfers of aid. Second, lobbying action by NGOs is fully justified by the inaction of states. Third, there is the impact of individual agency, the conscientizing impact of change in the esteem of disabled people on themselves and the society in which they live.

Public action has been needs-based, although a radically different conception of needs from those of the “basic needs” approach to which it owes some of its intellectual ancestry.²⁷ The United Nations lists the basic needs of disabled people as self-care, mobility, communication, education, income generation, social integration, participation and representation and legal security (Helander, 1993:37-41). The paternalistic provision of services and goods which enhance the quality of disabled people’s lives does not enhance their freedom in the absence of consultation with them (Cohen, 1994). Participation is equally a counter to élite domination and a means to establish relevant action.²⁸ But consultation can produce unexpected results. Disabled adults in Uganda consulted about their needs prioritized them as follows: income, housing, transport, sex. Rights to redistributive provision

²⁷ The goods identified by “basic needs” which are instrumental to a minimum standard of decency are: food, health care, shelter, water and clothing (Streeten, 1981). Although this approach has received criticism *inter alia* on grounds that the list is not justified, in fact it accords closely with Sen’s basic capabilities and with Rawls’ principle of action to the greatest benefit of the least advantaged (Qizilbash, 1995). There is therefore consensus on a large territory for policy (Gasper, 1995).

²⁸ Qizilbash (1995) referring to the work of Goulet (1989) and Nussbaum and Sen (1989).

such as envisaged by the mainstream basic needs approach (Stewart, 1989) were (with the exception of housing) either unwanted by, or inconceivable to, those surveyed; and rehabilitation came a bad fifth (Action on Disability and Development, quoted in Coleridge, 1993:83).²⁹ Those surveyed put the right to exercise agency in paramount position.

Action on Disability and Development is an example of a new type of confederation of NGOs and self-help groups organized by about 600 disabled people themselves campaigning for the right to earn a living, loans, pensions, appropriate transport (subsidized transport passes), orthopaedic support, and for (scholarships for) education and training.³⁰ Public action has also been effective at exposing and countering discrimination, ignorance and fear (see Barnes, 1992, for a careful compilation of the institutionalized discrimination practised in Britain).

Needs-based advocacy is generally combined with practical action on skilling and services which support the empowerment of disabled people. As with environmental issues, coalitions between technically and professionally qualified activists in support of movements of disabled people prove effective.³¹ In India “social action” is a socially recognized label for a form of politics and disabled activists can be supported by a wider constituency.

The problems faced by these new movements of disabled people are legion. If their aim is social integration, it is argued that there is no point to creating a separatist movement. The splintered nature of this movement of self-advocacy may give rise to competition for scarce resources. There is no all-India disability movement or federation. The need to co-opt non-disabled and carers (who also have economic and social needs) makes such movements vulnerable to capture by paternalists (“benevolent oppressors”) (Coleridge, 1993:61). Both carers and the able bodied react negatively to militancy by disabled people. The latter have an uneven capacity to communicate orally: the blind and physically disabled are not hindered, but deaf/dumb and mentally disabled face great difficulty in communicating in the public domain. Finally, the vagueness of Indian law, analysed earlier, is a problem for mobilization.

“Equal opportunity” would almost always mean removal from the unskilled labour force, a process experienced as a privilege by able bodied, assetless,

²⁹ Disabled children (who might have been expected to prioritize education) were not covered. The priority of rehabilitation will clearly depend on the type of disability, the age at onset and the previous contact of disabled people with the concept and/or with a rehabilitative institution. The relationship between disabilities, sexuality, the sexual needs and reproductive rights of disabled people is a taboo subject in the literature bearing on development. The subject of sexuality is dealt with under the heading of “gender” by Helander for UNDP and not at all by Coleridge for Oxfam. There is, of course, a literature on the disabling consequences of female circumcision and infibulation.

³⁰ Elsewhere (in Southern Africa) there are federated NGOs set up by disabled people to promote self-help groups and train disabled leaders, to facilitate information exchange through public education, consumer control and cross-disability empowerment (Charlton, 1991:48).

³¹ Coalitions of professional activists and vulnerable and threatened people are recognized to have been effective in the case of gender and environmental protest such as embodied in the Chipko Movement, but also in the organized opposition to the Narmada River Project and in social movements against bonded and child labour and the exploitation of tribal people (Jayantha Bandhyopadhyay and Vasudha Dhagamwar, personal communications, 1993; Medha Patkar lecture, Madras Institute of Development Studies, October 1993).

unskilled people.³² This is not to argue against “equal opportunity” as a goal for mobilization but to recognize that its political effects will be analogous to the selective incorporation of some landless labourers into a land reform programme.

3.2.2 The cases for the developmental state

These are not cases against CBR or disabled people’s movements but ones in favour of supplementing voluntary, individual and charitable provision with statutory, standardized, generalized and regulated professional services.

There are four cases. The first, the **economic**, requires challenge to the assumptions that cost-benefit ratios for disability projects are mediocre and that the state delivery systems are less appropriate than those of NGOs. In the view of this writer, this argument is the weakest, because cost-benefit analysis and its discourse are unable to value the types of benefit central to the therapeutic experience of disabled people.³³ For this reason, it is difficult to identify achievable and measurable end-states by which to evaluate cost effectiveness. It is also a weak argument because certain kinds of disability are unrehabilitative in narrow economic terms and will not produce positive cost-benefit ratios.

That said, and mindful of reservations about CBR, cost-benefit analyses of CBR programmes for adults of working age have shown five-year economic returns per unit of investment of between 2.9 and 9.2 (Hammerman and Maikowski, 1981:134-147). CBR is not a low-cost intervention. In particular, the analytically neglected transactions costs of self-selection, development and discovery, and the “non-training related coverage” costs involving other people than those targeted are high (Berman and Sisler, 1984). However, Helander puts the “per client” costs of segregated institutions at around US\$ 5,000 per capita, while CBR varies between US\$ 17 and 64 (1993:120 and 161-166). Cost-benefit analyses of preventive programmes normally show high costs and high rates of return.³⁴

So appropriate investments in the (re)habilitation of selected disabled people can provide high rates of economic as well as social benefit. Rather than valuing disabled people as waste in a value system dominated by economic efficiency, it is proved to be wasteful **not** to habilitate such disabled people.

The second element is a **public goods argument**. Theoretical debate on health policy has revolved around the question of whether health is properly considered a public good to be provided by the state or could be left to private provision via the market. The positive case for the well-being of

³² That special concessions to disabled people are seen as privileges — not as equalizing rights and access — is widely experienced in developed countries; as for instance abuse of the orange car card system, which enables the disabled drivers to park in places proscribed for able bodied drivers and passengers, and the usurping of parking spaces designated for disabled drivers and passengers only.

³³ Unvalorized work by the elderly, the young and women, self-respect, reduced psychological burdens on families, etc., as discussed earlier in this paper.

³⁴ For example, the oncocerciasis (river blindness) eradication project whose main beneficiaries are subsistence farmers in sub Saharan Africa (costing US\$ 570 million with a 28 per cent internal rate of return) (see World Bank, 1993:27 for this and other examples).

disabled people as a public good rests on the same argument as for health. With respect to preventive action (such as iodization of salt) gains or losses are social and there is no incentive for individual action. It follows that the divergence of private and social benefit will lead to such under-provision in the market that preventive health care and health options need to be provided at zero private cost by the state. Even information about provision for disabled people, preventive and curative therapy, has to be a public good and cannot be optimally provided by market mechanisms.

The negative case derives from the fact that markets for therapy and rehabilitation misbehave in crucial respects. Consumers are usually ignorant rather than sovereign. Search costs for buyers render therapy a seller's market and one, moreover, with no quality norms. Demand is uncertain. Market entry is episodic and involuntary — consumers cannot maximize utility.

The third strand is an **equity argument** in favour of the state's providing therapy and, in so doing, redistributing social income. Financial transfers and the donation of voluntary labour through the voluntary sector is on a disproportionately small scale compared with resources available to the state. For reasons given above, it is impossible to obtain a competitive market in therapy or rehabilitation.³⁵ Private social and/or health insurance breaks down in high risk conditions typified by poor populations. It is the case in favour of health as a public good which is *de facto* accepted in the Indian constitution, but the connection between health and therapy for disabled people was not made there. The need for debate, however, is continually provoked by the absence of rights for disabled people, by deformities in policy practice and in the social distribution of disabling conditions.

The fourth case for the state is an **ethical argument**. The trouble is what kind of ethical argument. Since utilitarian ethics takes a subjective view of desirable action which cannot be matched with what is objectively required for the fulfilment of people's lives — in Sen's words, for their capability and functioning (Sen, 1990) — utilitarianism is of no value for an ethical argument that the needs of disabled people should take priority over the private pursuit of satisfaction.

Rights-based arguments marginalize need,³⁶ since we have seen exhaustively here that the meeting of people's needs requires interference. For interference to be practicable, for policy to be implemented, institutions of obligation have to exist (Helander, 1993:50). We have seen here that a libertarian concept of rights which denies universal obligation but accepts a role of individual acts of charity is completely inadequate, because the conditions of disabled people require reliable, large and sustained funding resources historically quite untypical of charities. It is also not possible to measure people's rights in such a way that conditions of maximum liberty can be identified or compared as between individuals.

³⁵ Just as it is impossible to fund a set of distributive measures which do not affect resource allocation and income distribution.

³⁶ Individualizing needs and rights is a symbolic, normative act in a society where most people face life as members of family, kinship and caste networks within which they have overwhelmingly important and mutual obligations and claims.

The welfare conception of rights recognizes a universal obligation to match universal rights to those needs without which individuals forfeit their capacity to be social beings (O'Neill, 1994). This argument falls foul of the empirical test, for there is evidently no universal institutional obligation (Alston, 1994).

The residual rights-based argument is its virtual mirror opposite: namely that even though rights cannot be claimed, society has an obligation, albeit a non-universalizable and imperfect obligation, to act so as to realize the capacity of disabled people to be social agents, and to refrain from actions preventing this from happening (O'Neill, 1994). We saw above that this argument, translated into a developmental objective, is precisely what disabled people articulated when they were consulted. The internationalization of development discourse and law has resulted in a great expenditure of effort to identify universal basic needs, basic capabilities or the values defining "good life" (Qizilbash, 1995). This ethical development project is inconclusive, because to be a "social agent" is a culturally specific attribute. There may well be a plurality of types of social agency within one society³⁷. The detail of desirable and appropriate agency, and of relevant areas of experience will differ over time and between societies. However, nowhere is this exercise of agency anti-social. To the extent that discourse, culture and values are internationalized, a core or agenda of practical, political actions can be agreed. But at the end of the twentieth century, no other institution but the state can either develop and institutionalize this imperfect obligation or operationalize this imperfectly defined social agency towards those within society who are disabled. Only the state (and perhaps the media) can endorse changes in the social attitudes towards disability of both the disabled and the able bodied.

◆ 3.3 An Agenda for Disability

Robert Kates, the Director of the Brown University World Hunger Program has recently made a statement which is painful in its honesty about international advocacy, concluding "Not only is it difficult to pursue a credible science, but it is even more difficult to be an effective social policy advocate" ("Divisions in the hunger industry", 1993). In attempting to sort out the reasons for such a situation, he reveals the intellectual corruption that academic research strains to avoid in its dialogue with social policy and politics.

The translation of research to policy confronts the fact that to enter the policy arena, presentational procedure is paramount. Kates identified as crucial in the advocacy work of his particular programme the choices between advocacy of incremental or fundamental directed change, which he termed optimistic or pessimistic advocacy. Selective and contingent use of evidence is unavoidable; even so, "policy outcomes" are uncertain. Low estimates of the malnourished make the problem appear tractable or insignificant; high estimates may lower priority due to administrative

³⁷ Jacobs (1993) distinguishes two public ethics each associated with a sector of the modern economy: commerce and government.

fatigue.³⁸ It is evident that what Kates calls the “hunger industry” is not simply a political technocracy in its own right, it has its own internal politics. Exactly the same is true for disability.

The United Nations is itself handicapped as an instrument of social change because of the depoliticized and generalized discourse it is compelled to use. By contrast, the raising of the low position of disability on social welfare — let alone developmental — agendas is a competitive political practice involving the deprioritization of some other developmental goal.

It is worth setting down the main factors preventing society from being non-disabling, which are, or can be, the responsibility of the state, consistent with the objective of imperfect obligation:

- **Language and discourse** — This concerns the grey area between the tyranny of political correctness and the respectful, unprejudiced usage of language. Since language is a cultural artifact, there can be no universal argument — in the United Kingdom, for instance, propriety involves the substitution of personal language (disabled people, personal names) for objectified abstractions (the disabled, a leper, a cripple); but reference to people by their physical characteristics may be a normal practice in other cultures: “the lame one” may not be disrespectful or patronizing.
- **Law** — There is a lack of an enforceable legal and administrative institutional mechanism for disabled people to exercise rights and obtain redress for justified grievances.
- **Administration** — This involves modifying public administration and departmental agendas so that disabled people are not routinely involved throughout the public sector and in every aspect of public policy and expenditure.

Logically, then, we have no idea what a further policy programme derived from consultation might contain, but the following are derived from principles of provision of a non-discriminatory environment for the expression of social agency:

- **Health** — might involve gender-sensitive, decentralized, free, public primary health; improvements in obstetric practice; an increase in primary health professional personnel and in appropriate technical equipment;
- **Food and nutrition** — only two major causes and effects have been established: Vitamin A (blindness) and iodine (deficiency of thyroid gland functions leading to cretinism). Iodization technology is necessary but insufficient when unaccompanied by a delivery system;
- **Education** — the sensitization to disability (as to gender and race) of mainstream teachers, the provision of resource centres for teachers and

³⁸ See Payne and Pacey (1984) for a full discussion of the presentational problem in relation to nutrition policy.

adequate provision for students with special needs, an increase in professional personnel;

- **Work and environment-related preventive action** — universal immunization, job quotas for disabled people throughout the organized sector and positive incentives (the Japanese system, for instance, features grants for the creation of private sector work facilities, on-the-job adjustment) training and management, communications and transport technology, architectural-environmental standards;
- **Welfare** — graded social benefit systems extending outside the system of formal or organized employment and not penalizing the disabled person from active participation where this is possible;
- **Research** — social cost-benefit analysis and cost effectiveness analysis is needed on a range of institutional alternatives together with evaluation in terms other than present net values or internal rates of return: relevance, institutional sustainability, social impact, interests served or ranged against such options (Helander, 1993:173-82). The questions of what people of different age, gender and social class with different types and severities do; what they produce, whether and how they socially reproduce; what they and their carers want and how best to develop capacities to obtain those objectives and realize that agency need urgently to be addressed, as does the role of non-politically neutral technical advice in different types of social order (e.g. under market socialist conditions, under those of Japanese or East Asian models or under conditions of market led development).

Charities performing services for such a state would be likely to be improved by reform into agencies contracting for and providing public services under regulation of standards and terms and conditions of employment.

4. CONCLUSIONS

It is society which is disabling rather than people who are disabled. Development means the social change which weakens 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 — for example, rights and citizenship, the social and material preconditions for freedom, the exercise of agency and enjoyment, the question of the class-space assumed in the notions of “participation” and “integration”, the definition of health?

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 low caste, disability is stigmatizing regardless of economic status. 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 developmental issues in part because of the impacts upon international development institutions of feminist and environmental professionals and of social movements created and/or sustained by them in **developed** countries. 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 and of international aid agencies is thus even more necessary.

If development is self-realization through social agency as well as material improvement, then the condition of disabled people provides sets of sensitive indicators. Response to the experienced indignities of disability requires changes in public ethics, but if public ethics were changed and if political institutions came to reflect an intensified social accountability, then other pathologies such as widespread tax evasion, economic crime and political and bureaucratic corruption would also be alleviated.

Policy makers and economists who call for accountability or “political will” in single and weak parts of the state without addressing the issue of the accountability of the state as a whole and society at large are acting without responsibility. The notion of the private interest state embodied in public choice theory becomes cynically self-fulfilling and can be seen to serve the interest of those who would deny all but one form of politics their legitimacy.

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