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Selected Issues Surrounding the Identity and Social Valuation of Disabled People in Contemporary Industrial Society

ABSTRACT

This paper represents a review of a wide range of the literature available to support a proposed in-depth study of issues arising from recent advances in genetic science, with the focus on the identity and (dis-?)valuation of disabled people. Although many 'standard' texts are visited, space has been made to include a survey of authorities from a wider than is common spread of academic disciplines, with the specific intention of broadening the knowledge base to be interrogated. To this end, brief excursions are made into the domains of psychology, molecular biology and both secular and religious ethics, alongside the more familiar territory of sociology, social policy and disability studies. The mechanics of identity formation and social value assignment are explored in Section 1, whilst Section 2 examines ethical approaches to disabled and disvalued people, drawing attention to the areas of eugenics and genetics. Section 3, building on the foregoing, appraises the notion of 'value' as assigned to disabled people in contemporary society. It is not, however, intended that this review should be seen as exhaustive, for the pool of theoretical and experiential knowledge is vast - this is a sampling exercise. This having been said, the present work is also an integral part of a taught Masters programme. Consequently, the format is more coherent than may be expected of a 'simple' literature review, with analysis, argument and comment interwoven with the mere description of the opinions and findings advanced by individual authorities. Sources are compared and contrasted, and ultimately a synthesis of the differing approaches is offered with, it is claimed, some degree of predictive power regarding the possible outcomes for disabled people of current trends within medico-scientific research, diagnostics and therapeutics.

Introduction

This work, on its major level, is intended as a precursor to a proposed empirical research project into the effects on disabled people of continuing genetic research. It thus represents an exploration and review of some of the extant literature (including press reports) and opinion in the area surrounding the assigned and self identities of disabled people, and the relative social values accorded to them, especially in the light of increasing genetic expertise flowing from the Human Genome Project (HGP). On another level, the work is an integral part of a taught course, and is designed as a 'stand alone' paper. It will, therefore, examine and test the varied strands of argument which have been advanced in the relevant areas, drawing on sources from Britain, America and mainland Europe.

Whilst several of the stalwarts of Disability Studies appear here, for example Abberley, Barnes, Hunt, Morris and Oliver, others do not feature. This does not imply that they have nothing valuable to add - it is simply due to the constraints of word-limits, and their sacrifice is to allow for a more detailed summary of the work of others, for example Bauman and Lifton, who do not appear to have been cited within this discipline, and the psychologists Asch, Milgram and Zimbardo who have rarely if ever appeared. Due to the concern here with aspects of genetic research several sources are cited from other disciplines which may be loosely termed 'medico-scientific'. Whilst it is difficult to avoid 'reinventing the wheel' there is a conscious effort in this work to point towards a broader knowledge base which may be interrogated; a search for wider horizons to scan, or a deeper well to draw from.

Although acquired impairment is the major component of the phenomenon of disability, it is clear that the debate relating to selective abortion relies almost exclusively on the diagnosis of congenital impairment, increasingly with a genetic emphasis. Infanticide represents here a crossover situation, with some candidates selected as a result of congenital conditions, others following injury or mishap in the

womb or during the birthing process. Euthanasia (as distinct from infanticide) is, perhaps, more closely linked to terminal illness, rather than impairment, although it has clear and direct applications to disabled people. Whilst much of this paper will necessarily be concerned with issues arising from congenital impairment, this ought not to be taken as inferring that this form of impairment is in some qualitative way 'different' to acquired impairment. This work is informed by Social Model Theory, and the primary focus remains the social construction of disability, not any medical evaluation or description of impairment. The evidence of Shakespeare introduced in Section 3 suggests that there are grounds to fear that one result of genetic research may be to introduce differentials into the way certain impairments are viewed by society. If this fear were to be realised this is clearly a matter of concern for Social Modellists.

A major indicator, it is claimed here, of the social value assigned to any particular group of people is to be found in the lengths to which society in general, and Government in particular, is prepared to go to protect the human rights of that group. Indeed, this notion underlies the various 'rights' movements - notably of black people, of women and more recently of disabled people - which have been a feature of western society throughout much of the twentieth century. Nonetheless, 'rights', here, remain subordinate to the issue of 'value'.

The topic of social identity is intimately related to any idea of social value, and Section 1 below concerns itself with this area, specifically in relation to disabled people. It will be demonstrated that identity is not some objective 'fact', but is derived from a subjective social process which, it is argued here, is informed by a derivative of labelling theory, although the complexities of this sociological theory will not be tested to any great depth. The interplay between impairment, identity and social process is the primary focus, and here the psychoanalytic work of Lifton is given prominence.

Section 2 looks in some detail at the arguments, and particularly the ethical justifications deployed, in the ongoing debate(s) around the issues of euthanasia, assisted suicide, (eugenic) infanticide and selective abortion. Not surprisingly, Singer and the Nazis appear (no connection is implied), and parallels are drawn between eugenic and genetic mind-sets. However, euthanasia, *etc.*, whilst each is of profound significance in its own right, serve here collectively as an indicator of the relative social value assigned by society to disabled people: a convenient peg from which to hang the wider discussion. The Section concludes with a brief appraisal of the underlying tenets of genetic counselling.

Section 3, drawing on the preceding sections, examines directly the notion of value as applied to disabled people within western society, introducing an idea that the cumulative effect of the social forces said to be operative may tend towards their *dis*personalisation and *dis*valuation. The works of (Tom) Shakespeare and Wolfensberger are given some prominence, although a wider view is fostered, with an emphasis on the sociology of Bauman regarding the bureaucratic processes underlying present society. Sources from within the field of medico-science are interrogated, the better to provide a panorama. Despite the dangers of prophesy, the perceived effects of present policy and social processes upon disabled people will be examined, as, it will be alleged, their value to society is further eroded or, perhaps, removed altogether.

Due to the nature of this paper, the research technique employed is one of content analysis of the various sources consulted. The media vary from books, through journals, academic papers, press releases and reports, to electronically published 'papers'.

Impaired Identity or Identity Impairment?

The self is not so much a substance as a process...

{Mead 1934 p178}

We are all influenced by the values of the society in which we live.

{Morris 1991 p43}

'Identity' is a crucial part of social life for, as Goffman {1963 ch1} notes, social interactions are conducted, on both sides, on the basis of the relative identities of the participants. In effect, social identity is for Goffman a shorthand representation of those attributes which we confidently expect another person to display, be they positive or negative. At its vaguest, 'identity' is subsumed within, and to some extent derived from, such sociological descriptives as 'class', 'caste' or 'status' all of which, in one way or another, describe social inequalties {eg Crompton 1993}.

As used here 'identity' ignores the finer social constructions, acting more in the nature of a switch which is either 'on' or 'off': an individual is 'identified' as being either inside or outside the social framework of 'normality'. Hence an 'outside' identity is impaired, in the sense that it does not admit the bearer to full participation in society. It is argued here that bodily impairment translates, by social processes, into identity impairment, a point accepted by Goffman {1963 p4} with his talk of *"abominations of the body - the various physical deformities"* which, for him, may lead to the *"stigmatisation"* of an individual who is demonstrably not one of the *"normals"* in society.

Mechanics of Identification

The means by which social identity is formed and reinforced have been subjected to much investigation within the disciplines of Sociology and Psychology, and this is not the place to rehearse the minutiae of the processes in train. There is, in both fields, a well-supported opinion that identity ensues from social processes, a view which has led to a theory of labelling as being an important part of the mechanics of the situation. (This process is evident in the work of Goffman {1963}). For the present purpose, and drawing upon the authorities cited below, it will be accepted that social labelling is both active and potent. This is readily apparent in the case of assigned identity - the designation of groups in society as 'mainstream' or 'other'; 'good' or 'bad' - and the possible deleterious consequences of a label of

'other' have been well-documented, observationally (eg Nazi excesses; genocide in modern Africa or the Balkans), psychologically (eg Asch 1952, Milgram 1977) and sociologically (eg Bauman 1989).

> [1]There is much more to the labelling process than assigned identity, however, for
>
> > [o]*ur sense of identity is constructed on the basis of other people's definitions* {Oliver & Barnes 1998 p67},

an idea current within behavioural psychology since at least the 1930s, *viz*

> [t]*he self... ... is a process in which the individual is continually adjusting himself* (sic)*... to the situation to which he belongs, and reacting back on it.* {Mead 1934 p182}.

It is noticeable here that Mead appears to accept that society has, if not the 'right' then at least the power, to assign identity - "*the situation to which he belongs*" - and that the person so labelled is in general passive in accepting the authority of the host society: assigned identity is readily internalised. Whilst there have always been dissenters and revolutionaries, to some extent this view has been vindicated by later events: the Jews in Nazi Germany were remarkably co-operative in accepting the atrocities heaped upon them; only a very small minority of disabled people are activists. The other side of this particular coin depicts the ease with which members of the social 'mainstream', who consider themselves to be 'normal', accept the validity of the labels applied to 'others'.

This ready acceptance of 'social authority' lies at the heart of Bauman's sociological work on the Holocaust {Bauman 1989}, wherein he makes much of the concept of 'otherness' and the dangers inherent in being labelled as not 'normal' or 'mainstream', and the psychological works of Asch {1952}, Milgram {1977} and Zimbardo {1969}. Of these latter, Asch demonstrated empirically what has for long been a 'commonsense' concept, that people frequently display a 'herd instinct' whereby they are willing to suspend their critical faculties the better to gain or retain

the approval of a peer group. The corollary, reported by Asch, is that those who insist on their personal interpretation of an event, even where accurate, risk the animosity of the majority. In some instances, such individualists became social outcasts, despite the fact that the issue was a trivial one of estimating the relative lengths of lines in a diagram.

Milgram {1977}, experimenting during the early 1960s, focused more on the perception of 'authority', and particularly on the high status identity assigned to medico-science. The important results for the present purpose were that randomly selected members of society displayed an almost unquestioning obedience to the instructions of a white-coated researcher, even to the extent of inflicting (unknown to them, simulated) pain on a third party, and that increased distance, physical or social, led to a lessening of restraint. However, Zimbardo's 1960s work on 'prisoners and guards' in the "Stanford Prison Experiment" is perhaps the most telling - the experiment was famously curtailed because the roles were entered into with over-enthusiasm.

Here, as described by Haney *et al* {1973} (reported in Gross {1994 pps 98-121}), volunteers were randomly assigned identities as either 'prisoners' or 'guards'. These assigned identities were rapidly internalised by all parties, to the extent that 'prisoners' became apathetic and subservient, 'guards' authoritarian to the point of physical bullying and the introduction of petty rules designed merely to underline their power, including a 'dress code' for prisoners. Tellingly, Haney *et al* {Gross 1994 p111} comment upon the

> *arbitrary control...for even the daily, commonplace functions like going*
> *to the toilet*

imposed by the 'guards' which, in the words of the researchers, very rapidly led to *"dependency and emasculation"* (all the subjects were male) on the part of the 'prisoners'. Thus one consequence of an assigned identity as a socially inferior 'prisoner' was a lowering of self-esteem.

This situation is analogous to that described by Hunt {1966 p151}, talking of disabled people's *"constant experience of...pressure towards unthinking conformity"* and {op cit p154} of

> *staff who bully...who dictate what clothes people should wear... ...and will take away 'privileges' (like getting up for the day) when they choose.*

Although Hunt spoke of institutionalised 'care', similar complaints have been made about 'care in the community', and Abberley {1987} constructed his theory of the *"oppression"* of disabled people around the lack of autonomy granted to them, the *"pressure towards unthinking conformity*" of Hunt.

The dual process of assignation and internalisation of identity is clearly demonstrated by a research project undertaken to study survivors of the Hiroshima atomic bomb {Lifton 1971}. Writing from an American psychoanalytic perspective, with a major focus on the psychological effects of nuclear warfare, Lifton incidentally presents a concise review of the sociological processes involved in ('impaired') identity formation. An important factor here is that, prior to August 6th 1945, atomic bomb survivors (*hibakusha*) as a group, or even as a concept, were unknown. There is, then, no centuries-long accumulation of ideological or cultural baggage to impede the view of the processes involved (Lifton is at pains to demonstrate that the socio-psychological effects are *not* unique to Japanese society).

That the *hibakusha* of Hiroshima fit the Social Model definition of disabled people is clear from the narrative {Lifton 1971}: they are grossly over-represented in the lower socio-economic strata of society {op cit p179}; they are considered a 'poor prospect' for marriage and frequently marry beneath their pre-*hibakusha* status {op cit p195} (in Japan this indicates a severe loss of social standing); they are routinely discriminated against in employment and workplace promotion, and frequently accept work which is associated with lower social origins than their own {op cit p180}. In short, they are subject to *"socio-economic deprivation"* {op cit p114} on

the sole basis of perceived impairment. This indicates that the *hibakusha* identity is an impaired one: the holder is *no longer* a full member of society. Indeed, Lifton {op cit p181} cites cases of *hibakusha* voluntarily joining *"the ranks of the outcasts"*, the slum dwellers of Hiroshima, effectively relinquishing all social standing.

A major consequence of this discrimination, in the psychoanalytic view of Lifton {1971}, is that *hibakusha* have themselves developed a lowered sense of self-esteem. In the idiom of Mead {1934 p182}, they have *"reacted back"* on the social processes to which they have been exposed, to the extent that they feel a necessity to justify the oppression which they have faced:

> [i]*t can't be helped. ...It is only natural...to employ healthy people*
> {*hibakusha* cited by Lifton 1971 p182}.

For Lifton this attitude represents the complete internalisation of the identity 'manufactured' by social processes for the *hibakusha*: they have come to see themselves as devalued, as intrinsically inferior, within their host society. This is despite a lack of evidence of any statistical propensity to medium- to long-term increases in morbidity or incapacity. Although in the short-term many *hibakusha* died of radiation effects, Lifton {1971} finds nothing to suggest that survivors of longer standing face any greater risk than the general population.

There are striking similarities between Lifton {1971} and Abberley's {1987} thesis of the oppression of disabled people by and within western society. For Abberley, disabled people are prevented from playing a full role within society, and are subject, as are the *hibakusha*, to *"social, financial, environmental and psychological disadvantages"* {Abberley 1987 p17}. An integral part of Abberley's argument relies on an assumption that people with impairments

> *can be regarded as a group whose members are in an inferior position*
> *to other members of society because they are disabled people* {op cit
> p7},

which implies both that a labelling process is in action and that a lower social value is

assigned to disabled people. Indeed, the parallels between disabled people and *hibakusha* are inescapable: identity is assigned by society, internalised by individuals. (A similar view is advanced by Shakespeare {1996}).

Motivations

Abberley {1987}, Oliver {1990 *et al*} and Finkelstein {1993}, amongst others, firmly point to capitalist ideological pressures as informing the processes which lead to an 'impaired' identity, essentially as someone who is of no or limited value to the industrial system. Stone {1984}, adopting a longer historical view, looks more to market forces, and in particular mechanisms of wealth distribution, with the emphasis on the perceived dependency and vulnerability of disabled people. Barnes {1996 *et al*}, although admitting a role for capitalism, tends more towards a cultural explanation, especially as disability discrimination may be discerned in pre-capitalist societies. Meanwhile, Shakespeare {1994} strongly supports cultural effects in the propagation of disability discrimination.

Hunt {1966}, whilst pointing to capitalist ideological influences, implicitly proposes an essentially cultural cause for 'impaired identity': he sees disabled people as posing a challenge to 'normal' society. Although Hunt at first finds five forms to this challenge, in that disabled people confront society as being *"unfortunate, useless, different, oppressed and sick"* {op cit p146}, which he links to capitalist values, he later reduces this to a nub which is unmistakably cultural:

> [c]*ontact with us throws up in people's faces the fact of sickness and death in the world* {op cit p156}.

Thus Hunt hints at a culture which lionises health and bodily strength, and a socio-psychology which prefers to 'forget' mortality. Here, Hunt could well have been summarising Lifton's {1971} thesis (titled *"Death in Life"*), for the major argument of Lifton is that the *hibakusha* are excluded and discriminated against, oppressed, precisely because they are tainted with 'sickness and death'.

From his empirical work with both *hibakusha* and their non-exposed contemporaries Lifton {1971} is able to demonstrate that this 'taint' of human mortality is the driving force, not only in the socio-economic exclusion of the *hibakusha* but also in their apparent acceptance of their downgraded status:

> *the death-tainted are a threat, an enemy, and finally, an inferior breed*
> {op cit p182}.

Hibakusha, as disabled people more generally, are first and foremost members of their host society: they have internalised, as part of their primary socialisation, many of the attitudes and values of that society {*cf* Hunt 1966, Morris 1991}. Just as the *hibakusha*, in general, acquired their devalued status so, it must be recalled, the majority of disabled people were not born with an apparent impairment {Abberley 1987 p15}. In both cases, primary socialisation was on the basis of assumed 'normality'.

A major inference to be drawn from the observations of Hunt and Lifton is that the human psyche (in psychology, itself a product of complex dynamic processes), at least in industrial society, contains an innate revulsion for the symbolism of death and illness, whilst the works of Asch and Milgram referred to above strongly suggest that any who deviate from a dominant norm will be ostracised (a view which forms the basis of the theorisation of Oliver, Abberley *et al* regarding capitalist ideology). Zimbardo, meanwhile, teaches us that the labelling process is a dynamic one, a point reinforced by Lifton, who demonstrates that a previously unknown state, that of *hibakusha*, had, within days, been labelled as 'deviant'. The consequence for disabled people is that they are, arguably, discriminated against twice over, in the first instance as symbols of death, in the second as social deviants.

Inverting Impaired Identity

Oliver & Barnes {1998 ch2}, whilst broadly confirming the processes noted above, point to recent efforts by disabled people to gain some measure of control over

the forces in action, particularly in the areas of media and political representation. Lifton {1971} is able to offer insight into this growing awareness of disabled people, for there are actions and reactions in train. It is noticeable that disability activism has its roots in the 1960s, and it is commonplace within disability studies to attribute this to groundbreaking work done by the feminist and black rights movements. However, in Britain this was also a time of consolidation in notions of welfarism, with a corresponding increase in ideas of 'care' for disabled people, a regime which Hunt {1966, 1981} specifically rebels against. Meanwhile in America, Vietnam war-wounded veterans were at the forefront of disability activism, against a backdrop of increased programmes for their 'care' and 'rehabilitation', whilst Stone {1984} notes a general increase over time in western 'services' for disabled people. These 'improvements', seemingly paradoxically, appear to have been counterproductive in that disabled people became more vocal in their opposition to their 'treatment'.

Lifton {1971 p204 *et seq*} draws particular attention to the fact that the *hibakusha* are granted certain free services and benefits, most notably in terms of medical attention, which are denied to the general population (compare with Stone {1984 p28} on the *"privileges"* allowed disabled people). For Lifton {1971} this well-meaning action is negative in its impact upon the *hibakusha*, not only in terms of creating dependency but also at a deeper psychological level. Here, it appears, the granting of such 'privileges' acts to confer a *"constricted"* identity, to the extent that *"the experience becomes the person"* {op cit p205}. This is a depersonalising process akin to the reductionism employed in eugenic and genetic practices, and one which Hunt {1966 p146} describes as

> *the common fault of viewing people in terms of one characteristic to the exclusion of all others.*

However the process goes deeper than the relatively superficial (but nonetheless important) assignation of a 'constricted identity'. Noting that the *hibakusha* are portrayed as atomic bomb *victims* (a situation directly analogous to

that of disabled people, who may be seen as 'victims' of their impairment on a Medical Model assessment, 'victims' of society within the Social Model), Lifton {1971 p206} observes that

> *any identity based upon victimization is perceived as counterfeit, and the survivor's lifelong struggle against being* ***nothing but a hibakusha*** *is a struggle against counterfeit existence* (emphasis in original).

Thus where 'services' and 'care' for disabled people are offered on a basis of 'righting' some 'wrong', of assisting an 'innocent victim of circumstance', the effect is to underline and reinforce an 'impaired' identity. It is a disabling act which sets its recipient apart from the rest (with an implied 'best') of society. This *"struggle against counterfeit existence"* lies at the heart of disability activism, with its calls for equality of opportunity and full socio-economic inclusion for disabled people. Ultimately the call is for a 'legitimate' identity, one which signifies a position on the 'inside' of society: an identity which is not impaired.

This is not to deny that disabled people have particular social needs which ought to be met. Rather, it is to suggest that such needs be addressed within the context of a mutually supportive society which recognises that *all* have needs which lie along a continuum, and that no part of this continuum is in any way different to any other: all social needs are equally legitimate.

<u>Section 2</u>

<u>Ethical Pragmatism - or Pragmatic Ethics?</u>

How is the faithful city become an harlot! it was full of

judgement; righteousness lodged in it; but now

murderers. {Holy Bible, *Isiah* 1:21}

This section is concerned with ethical issues arising from the elimination of people, born or unborn, whose existence or continued existence has been decreed to be undesirable for a number of reasons - in the idiom of Section 1 those who have been assigned an 'impaired' identity. For the present purpose it will be assumed that 'human rights', chimeral as they may be, do indeed exist, at least in the abstract, within a society which is nominally 'democratic'. There is, however, an important precondition to any discussion involving 'human rights': one must define 'human'.

Humanity

There is a view, most strongly promulgated by the Catholic Church {John-Paul II 1991}, that human-ness begins with conception, that it is an intrinsic property of any member of the species Homo Sapiens at any stage of development. This is essentially the stance adopted by opponents of abortion *per se*. There is another popular usage that one is not 'fully' human until delivered alive from the womb, for example Morris {1991 p75} appears to support a notion of foetal 'rights' as lying on a sliding scale and increasing with length of gestation.

A third, and most crucial in terms of the present debate, definition of 'human' is that preferred by Singer {1993 p 87}: *"a rational and self-conscious being"* who is also a member of Homo Sapiens. It follows that, with definitions one and two above, once human-ness is attained, at whichever stage, that state cannot be rescinded, and any 'rights' remain intact throughout life. Singer's definition is importantly different: it is potentially transient in that, should rationality and self-consciousness be deemed irrevocably lost for whatever reason, then the former person may be said to have ceased to be 'human', and thus is at risk of having any 'human rights' previously assigned withdrawn. It follows explicitly from Singer's definition that the unborn, the new-born and the adult who is permanently non-rational and unself-conscious (comatose or not) are non-persons devoid of human rights {Singer 1993 passim}. In Section 3 below, this will be characterised as *dis*personalisation. This is not an

idiosyncratic view held only by academic philosophers: the Anglican Church of Canada (as reported by Shearer {1981 pps87/8}) has defined human-ness as requiring

> *the capability of man* (sic) *to relate to himself, to his neighbour and with God* [ie to be both conscious and self-conscious],

before concluding that

> [o]*ur senses and emotions lead us into the grave mistake of treating human-looking shapes as if they were human... ...the only way to treat* [them] *humanely is not to treat them as human* {ibid} (with uncomfortable echoes of witch- and heretic- burning).

Thus, at least for this branch of the Anglican Church, Singer is a true prophet.

Euthanasia, Infanticide and Abortion

Singer {1993 Ch7} identifies three forms of euthanasia; Voluntary (where the subject has actively sought death) {op cit p176}, Involuntary (where a competent person has not asked to die) {op cit p179} and Non-voluntary (where the subject cannot be consulted) {ibid}. This list, with the addition of Assisted Suicide, is used for discussion purposes by opponents of Singer {eg, Wolbring 1999}. Singer does not seek to defend involuntary euthanasia, averring that:

> *euthanasia is only justifiable if those killed either lack the ability to consent to death because they lack the capacity to understand the choice between their own continued existence or non-existence*; *or have the capacity...to make an informed, voluntary, and settled decision to die* [and have so decided] {Singer 1993 p201}.

In all contemporary western countries involuntary euthanasia is, legally, murder. Singer supports this *status quo*, with his advice to

> *treat the rule against involuntary euthanasia as...absolute* {ibid}.

There is a lack of clarity, both within academic and general usage, attached to the concept of 'euthanasia', and particularly to any distinction between 'assisted

suicide' and 'voluntary euthanasia' - in either case, the principal has chosen death. However Roy {2000} opines that 'suicide' only occurs in the *"absence of an incurable...disease"* which is inevitably fatal. Should such a disease be present, Roy argues that the patient's early death results from euthanasia which, for him, may be self-administered. A major consequence of Roy's argument is that impairment, of itself, does not and cannot justify euthanasia.

The internal logic of both Utilitarian (the prime mover in Singer's argument) and Individual Rights (present or tacitly assumed in much of the argument of disability activists) philosophies supports, to greater or lesser extent, a notion of personal rights, and for a competent person the right to death may be thought to be as basic a human right as that to life:- "[e]*veryone has a fundamental right to self-determination"* {Kluge undated}. (Western) religious ethics in contrast, and taking account of the supposed intentions of a supra-mundane Deity, tend here to deny *human* rights in favour of a belief that the 'Will of God' should not be thwarted by hastening death, that human life is sacred until *"life's natural end"* {John-Paul II 1991}. On this argument life, no matter how much the individual may wish for death, is a duty to be performed. It is the price to be paid for birth (but recall the dissenting Canadian opinion cited above).

There is another branch of ethics to be considered:- Medical Ethics. Here the view of the British Medical Association ethics committee is clear:

> *if doctors are authorised to kill or help kill, ... they acquire an additional role which is alien to the traditional one of healer* {BMA 1993 ch6 (current on website 28/6/00)}.

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> Similarly the American Medical Association declares
> *that physician-assisted suicide is unethical and fundamentally inconsistent with the pledge physicians make to devote themselves to healing...* {Bristow 1999}.

What *is* accepted as ethical is the provision of effective pain control (i.e. for the patient's welfare), even though a side-effect may be to shorten life {BMA 1993 ch6} - a fine line upon which to tread. The right of a *"competent patient"* to refuse any or all treatment, even if this inevitably results in death, is specifically affirmed {ibid and Bristow 1999}, and has recently been upheld in the English High Court {*Daily Express* 11/8/2000}.

Although in Britain suicide is no longer a crime, the act of assisting willing suicides who are physically incapable of achieving their ends is, as is the procuring or counselling of suicide (and hence, in legal terms, voluntary euthanasia) {Suicide Act 1961 Section 2, in Richman & Draycott 1980 vol 2 p 4202}. With the exception of The Netherlands, which has legalised euthanasia in certain circumstances, this is the general case throughout Europe and North America (a Canadian Senate committee, on a majority decision, recommended maintaining this *status quo* as recently as 1995, although that debate continues). The seeming inconsistency in allowing suicide but denying assistance for a lawful act is defended on the grounds that a vulnerable person may be pressured by another into adopting a course of action which is not truly voluntary.

The subject of infanticide (here, a special case of non-voluntary euthanasia) appears to be deliberately shrouded in mystery. Certainly Shearer {1981 p87}, Pfeiffer {1994} and Shakespeare {1995} allege that newborns with impairments are routinely left to die, but both the British and American Medical Associations are coy on the topic. Frost {1999} offers the view that, until the 1980s, *"standard medical treatment for curable disorders"* was frequently denied to Down Syndrome and *spina bifida* infants, with fatal results. Frost claims that this situation has now changed, at least in the USA, following a Court decision (*"Baby Doe"*) which effectively forbade non-treatment in many cases. For Frost, this ruling amounted to a declaration that the *"prospect of handicap (sic)"* was no longer to be considered a factor in deciding on a course of treatment (or non-treatment - infanticide, as

euthanasia, may be a matter of commission or omission).

In practical terms, Frost {1999} indicates that infanticide is still routinely practised, but that the qualifying criteria now revolve around decisions on whether or not treatment could be seen as being in the child's best interests. There may appear to be little real qualitative difference between decisions made on the basis of impairment and those made on the basis of the 'best interests' of a baby with presumed 'disability'. In either case medical professionals assume the competence to decide whether or not an individual life is 'worth living'. The infant has no rights, for Singer {1993}, to be considered.

Singer {1993 p191 et seq} is explicit about non-voluntary euthanasia. Talking of long-term comatose people he opines that:

> [t]*hey are not self-conscious, rational, or autonomous, and so considerations of a right to life or of respecting autonomy do not apply.*

Later {ibid} Singer addresses the case of those who are

> *conscious but not self-conscious...it is difficult to see the point of keeping such human beings alive if their life is...miserable.*

It is unclear who decides, and on what grounds, the meaning of 'miserable', but this is an important escalation in the argument, for here Singer admits (intellectual) *impairment* as possible grounds for 'non-voluntary euthanasia', thus moving the discussion from the 'general' to the 'disability' arena.

The counter arguments fall into two categories: those, whether medical or religious, depending upon the 'sanctity' of life already discussed above, and those which assert that the non self-aware do, in fact, possess rights, which may be claimed and argued on their behalf. From an individual rights perspective,

> *the comatose...may not be able to claim their rights...* [but] *claims can be made for them* {Beauchamp & Childress 1994 p72}.

This position is clearly at odds with that of Singer, although it does not follow

that non-voluntary euthanasia is ruled out *per se*. As Barnes {1998} remarks, *"One human being's right is another human being'*s *wrong"*, and it may be that the rights of someone else, partner, family member, even someone with a better chance of recovery who is in need of scarce medical equipment, will be found more compelling. The important point, on this view, is that the rights of a person who is either comatose or *"conscious but not self-conscious"* should be given equal consideration alongside the rights of others.

Singer {1993} has a straightforward approach to abortion: the foetus or embryo is non self-aware, and therefore has no right to life. The pregnant woman, on the other hand, has full rights, including the right to abort. This argument is extended by the "pro choice" lobby, with a foetus being likened to a tumour:

> *there are no rights of ... any piece of tissue growing within a woman, ... That which lives within the body of another can claim no prerogatives against its host* {Stubblefield 1994}.

The counter-argument, for foetal (and non-self-aware) rights, is most clearly stated (as an article of faith) by the Catholic Church as concerning

> *the inviolable right to life which belongs to every person from the moment of conception until life's natural end* {John Paul II 1991}.

However, advances in medical science have raised important questions as to the validity of such a fundamentalist view at both extremes of the life cycle: on the one hand are issues arising from 'unnatural' *in vitrio* conception, on the other are found problems arising from the use of techniques and machinery to, arguably, extend life beyond what would have been its 'natural end' (which may apply equally to a foetus, a newborn, a child or an adult).

A more balanced view is that of Morris {1991 p 75}:

> *another human being is involved and...the rights of the mother and the rights of the child may be in conflict.*

As Morris makes clear, she does not propose that abortion is 'wrong' *per se*. She does, however, accept that a foetus has rights which ought to be weighed during the decision making process, although these rights are not necessarily persuasive. This is a fundamental disagreement with Singer, and may be seen as developing the argument (above) of Beauchamp & Childress {1994} to include the unborn as a group on whose behalf rights may be claimed and argued.

Eugenics and Genetics

Although the founding of eugenics is usually ascribed to Galton {eg Hawkins 1987 p330, Kevles 1992 p5}, and is traceable to the 1859 work of his cousin Charles Darwin, Herbert Spencer did much to popularise the notion of social, as opposed to physical, evolution {Goldthorpe 1963, Andreski 1972, Coser & Rosenberg 1982}, and in fact coined the phrase *"survival of the fittest"* in 1852 {Goldthorpe 1963 p78}.

In a clear example of reductionism, Spencer {The Study of Sociology 1889, as reported in Andreski 1972 p35 et seq}, opines that a society may be viewed as an aggregate with a moral identity *"determined by the characters of the units"*. This idea of 'character' rapidly became synonymous with notions of 'class', and in particular led to an idea of the lower class(es) as being inherently inferior. The early eugenics movement pointed to the general lack of health and high mortality of the working class, and their sub-stratum the pauper class, as indicating the physical, mental and moral degeneracy of the lower classes in general. Hence Beatrice Webb, an ardent eugenicist, who reportedly described herself as

> *the cleverest member of one of the cleverest families in the cleverest*
> *class of the cleverest nation of the world* {Freedland 1997 p2},

was apparently in no doubt as to which social (or indeed ethnic) group should come to predominate genetically. Notably Webb, in her diaries {Mackenzie & Mackenzie 1983}, refers to Spencer and to the great influence which his thinking had on the founders of the British Eugenics Society. Essentially then, eugenics is founded on a reductionist philosophy with the whole allegedly determined purely by its parts. Ethically the underlying notion is Utilitarian, of the 'greater good' for society.

Notoriously, in Nazi Germany both positive and negative eugenics became a crusade towards 'racial purity', with Lebensborn 'stud farms' established to encourage the breeding, and socialisation, of 'perfect' examples of the Aryan race. However, it is claimed {Toland 1977 fn p764} that the Lebensborn project, established by Himmler,

"never realized anywhere near its full potential", largely because resources were concentrated on the negative eugenics of 'euthanasia' and the 'final solution' (murder of those deemed genetically 'undesirable' - it should not be overlooked that the original targets of the Nazi 'euthanasia' plans, before racism gained the ascendency, were those with intellectual and physical impairment {eg Morris 1991 ch2}).

The major plank of eugenic thought is seen to be that physical attributes, 'morality' and behaviour (and hence 'identity') are mechanistically pre- determined by inheritance. Social influences are denied or minimised, and it is explicitly assumed (*qv* Webb) that a particular class or sector of society has some innate ability to determine with infallibility what is, or is not, 'right' and 'proper':- to set the standards for all to meet and establish relative social values.

The modern science of genetics displays marked similarities to eugenic thought processes. Genetics has gone an important step further in that individual genes have been isolated and described. In this way, the reductionism fostered by eugenics has been focused ever more sharply on the specific genes said to either cause or indicate a propensity to develop particular conditions of mind or body. The continuity between eugenics and genetics is clearly illustrated in the field of genetic counselling.

Whilst official sources, for example the US Government Centers (sic) for Disease Control and Prevention [CDCP] in its *"Strategic Plan"* {CDCP 1997, current on website 17/7/00}, are clear that genetic counselling

> *... does not include preventing the birth of people with specific genotypes...,*

this statement is at odds with the apparent realities of the situation. For example, an American academic and bioethicist is unambiguous:

> [m]*uch of the profession of genetic counseling really centers around helping couples avoid the creation of fetuses or children that will have serious birth defects...* {Holme 1995 section II},

a view reinforced by Keller (1992 p296} with her comment that

> *"prevention" means preventing the births of individuals diagnosed as genetically aberrant - in a word, it means abortion.*

Meanwhile, the (USA) National Society of Genetic Counselors, in its electronically published *"Resolutions"* {2000}, whilst circumspect, is clear that

> [t]*he NSGC, as an organization, publicly supports a woman's right...to prenatal diagnosis and access to safe and legal abortion.*

Although genetic counselling may trace its independent roots to the early twentieth century, when it was very much a matter of computing probabilities using the methods developed by Mendel, it has received a major boost as the diagnostic tools which have derived from the Human Genome Project have been refined. It is clear that it may, whatever image it wishes to promote, be seen as the spiritual successor to the Eugenics movement, a finding supported by Shakespeare {1998 p666 *et seq*}.

Disability:- Dispersonalised and Disvalued?

a *community* comprises human beings of every degree of physical endowment, the ill-endowed as well as the healthy, the abnormal as well as the normal {Ford 1966 p37} (italics in original).

Section 1 above has dealt with some of the basic processes said to be involved in the formation of identity, and more specifically with what is termed there an 'impaired identity'. Section 2 has examined ethical issues raised by attitudes to euthanasia (which here includes infanticide and assisted suicide) and selective abortion, and has suggested that the approach to these topics owes much to a reductionist philosophy born of eugenics and fostered by modern day genetics. This final section will proceed to consider a synthesis of these issues, informed by labelling theory, as a means of describing and to some extent predicting the overall effects of genetic research upon disabled people in contemporary society.

Impersonal Impairment

Industrial society is, first and foremost, a bureaucracy, at both State and Commercial levels, and it is in many ways difficult to imagine a complex society taking any other form (although Post-Modernist theorists may well disagree). In a bureaucracy there is an inherent tendency to describe, categorise and count. Moreover, for Bauman {1989} the bureaucratic process is inevitably one of *"dehumanization"* whereby

> [r]*educed...to pure, quality-free measurements, human objects lose their*
> *distinctiveness* {op cit p103}.

The end result of this process, for Bauman, is that people become abstract categories, quantities to be manipulated - 'criminal', 'unemployed youth', 'single parent', 'Jew' or 'disabled' are amongst those labels which readily spring to mind. As Bauman explains, such categories cease to be 'human' and, in particular, lose any claim to 'rights'. Any such group has the potential to become problematic, to interfere with the *"smooth flow of bureaucratic routine"* {ibid}, and if so characterised risks being subjected to impersonal 'solutions' to what is perceived as an impersonal 'problem'. That disabled people are subjected to such a process is suggested by Stone {1984 p26 *et seq*}, who charts the rise of 'disability' as *"an administrative category"* within an increasingly bureaucratic State.

Bauman {1989} develops his argument as part of his sociological explanation of the genocide practised by the Nazis and uses it to suggest that the Holocaust resulted not so much from some ethical aberration, as from the bureaucratic 'fact' that a category is impersonal (*"it is only humans that may be objects of ethical propositions"* {op cit p 103}). It may appear that Bauman describes a process of *dis*personalisation. A danger, then, for disabled people lies in the tendency of society, and particularly medico-science, to view them not as people but as 'conditions' {eg Hunt 1966, Lifton 1971}. It may be thought that the development of genetic science, which reduces the 'condition' further to an 'abnormality' at the most basic level of molecular bio-chemistry, can only act to exacerbate any inherent dangers.

One aspect of the categorisation of disabled people as 'different' is illustrated by Morris {1991 ch2} as she draws attention to social attitudes towards suicide, abortion and euthanasia. Drawing heavily on Nazi 'eugenics' Morris points to a tendency of society, and particularly medico-science, to consider disabled people in the abstract. Here Morris notes that 'quality of life' decisions are almost invariably made by non-disabled people, who effectively send a message that, for many disabled people, their *"lives are not worth living"*. Such decisions are frequently made against a (Medical Model) background which implicitly assumes that society and its environs are in some way immutable 'givens' - the individual must fit social norms in order to be able to function as a person. It is against this backdrop that, making a distinction between the situation of a person ('disabled' or not) who is faced with imminent and painful death and that of someone with a 'normal' life span expectancy, Morris shows that, in the latter case, a desire for death is portrayed as a rational response to impairment on the part of disabled people, but as symptomatic of emotional imbalance in their 'normal' siblings {op cit p44}. For Morris, this situation, allied to the Nazi 'racial hygiene' programme, indicates that the lives of disabled people are *"devalued"* in modern society.

Of course, Bauman {1989} and, to a lesser extent, Morris {1991} refer to a

particular period in the history of a particular country during a time of authoritarian rule (although Hitler was democratically appointed). It may appear that this situation, deplorable as it may be, has little or no relevance to the relatively Liberal western democracies of the present ... but, the whole point of Bauman's analysis is that the Holocaust, as a process with its own momentum, derived not from a dictatorship but from the logical, inexorable, application of depersonalising bureaucratic procedures allied to the absence of ethical checks on the treatment of impersonal 'categories'. Meanwhile, Morris {1991 p48} demonstrates that many other Nation States operated laws requiring the compulsory sterilisation, on eugenic grounds, of many people with impairments. Of these, America had introduced such laws as early as 1907 {ibid}, and in fact Pfeiffer {1994}, who considers this issue in some depth, indicates that in several States of the USA such laws are still valid and enforced. Apparent contradictions between these eugenic laws and legislation such as the Americans With Disabilities Act have not received official acknowledgement.

The evidence is that disabled people remain subject to depersonalising, arguably on Bauman's analysis *dis*personalising, forces in present society, a fact which Morris {1991} (as does Hunt 1966) sees as leading inevitably to the social devaluation of disabled people. There is an argument here for the extension of the 'Medical' model to become, as it were, a 'Medico-bureaucratic Model of Disability'.

Modernism and Medicine - the bittersweet M & Ms?

'Modernism', for Wolfensberger {1994}, describes a social mind-set which is predominantly selfish and characterised by the collapse of ideas, or ideals, of altruism and co-operative living. The concept, however, goes beyond the mere passive absence of ideals and is forcefully portrayed as an actively malevolent social process which pursues a policy of *"deathmaking"* directed against devalued sectors of society. Disabled people feature prominently within this target group.

In an angry and emotional polemic Wolfensberger {1994} construes

'deathmaking' widely, including not only the direct actions of euthanasia, assisted suicide, infanticide and abortion, but also more or less subtle approaches such as the rationing of medical resources and the inappropriate prescription of powerful, potentially toxic, psychoactive drugs. Contentiously in Disability Studies circles, he strongly criticises {op cit p396} the *"dumping"* of certain disabled people from institutions into *"abandonment in the community"*, there to survive as best they can. The point here is that, unless proper and effective systems of support are in place, this 'abandonment' is, if not fatal, then at least a cause of great distress and results in unacceptably low standards of living, as these people are left with unmet needs in an uncaring 'community'.

The underlying thesis of Wolfensberger {1994} is that 'modernism' seeks to categorise groups of people as devalued, the better to facilitate their elimination from society. In this, and despite his religious tone, Wolfensberger is not far removed from the opinion of Bauman {1989} on the role of bureaucracy. Indeed, the value-set which Wolfensberger attributes to 'modernism' includes the decidedly bureaucratic notions of Utilitarianism and Materialism.

Another of these 'modernistic' values, *"Individualism"* {Wolfensberger 1994 p400}, which *"informs one...that one should pursue whatever one wants"*, is strongly reminiscent of the *"Narcissism"* of Lasch {1991, 1st pub 1979}. Lasch seeks to demonstrate the growth, during the final quarter of the twentieth century, of a rising sense of self-sufficiency within western society, without the need for the ties of community. Consequently, on this view, whatever spirit of co-operation may have existed previously is supplanted by fiercer competition. Interestingly, Lasch {op cit p44} opines that 'Narcissism' and bureaucracy, by jointly placing

> *a premium on the manipulation of interpersonal relations* [and discouraging] *the formation of deep personal attachments,*

reinforce one another in a dehumanising process. Although Lasch makes no reference to disability *per se*, he draws attention {op cit p 207 *et seq*} to a greatly increased fear

of death {cf Hunt 1966, Lifton 1971 Section 1 above} in contemporary society. It is not difficult to imagine this greater fear of death, if Hunt and Lifton are to be believed, as leading to the further devaluation of disabled people.

Meanwhile, medico-science (which it will be recalled Milgram {1977} found to be imbued with an air of 'authority'), and particularly genetic research, continues to emphasise the primacy of symptoms over personality. Just as for Bauman {1989} a bureaucratic category has no intrinsic rights, so it is claimed here that a 'condition', being impersonal, is denied those ethical considerations commonly granted to people. Ramsay {1994} expresses her concern that this approach represents medical reductionism, also pointing to the danger of introducing 'the normal' as a datum line. As Keller {1992 p 295 *et seq*} points out, in popular usage 'normal' is synonymous with 'average' and is therefore a flexible concept totally unsuitable as a yardstick. For Ramsay {1994}, echoing in part and reinforcing the views of Goffman {1963} and Hunt {1966}, reliance on an ill-defined normalcy may not only *result in improper descriptions, stigmatizations and social control"* {Ramsay 1994 p 244} of disabled people, but also leads to the neglect of *"social, economic and environmental factors"* {op cit p245} present in the disabling process. Ramsay is supported in this analysis, in the specific context of the Human Genome Project (HGP), by Magnus {1998}:

> [b]*iomedical reductionism leads us to focus research and therapeutic*
> *efforts on the genetic basis of disease...to the exclusion of efforts aimed*
> *at other levels.*

In the same context, Lippman {1994} also expresses her concern about the increasing use of genetic information to describe and label people. For her, genetics

> *promotes scientific control of the body, individualizes health problems*
> *and situates individuals...according to their genes* {op cit p144},

by a process which she names *geneticization.* This process has recently been endorsed by Clinton and Blair, with their joint triumphal statement {White House 2000} on the Human Genome Project, referring to

the human genome -- the genetic blueprint for human beings.

Geneticization is the very antithesis of Social Model thinking, at one and the same time firmly locating 'disability' in the individual and denying the validity of social process. Indeed, geneticization claims the ultimate triumph of 'nature' over 'nurture', as press releases proclaim a long list of genes 'for' seemingly every aspect of human difference, not only impairment or 'disease'. This way of viewing and labelling people as bags of genes amounts to the most severe form of reductionism possible. One ceases to be a person, becoming instead an impersonal collection of complex chemical molecules. Ultimately all are reduced to a label:- 'normal' or 'abnormal'. This is clearly a dispersonalising process.

Caplan {undated, current on www 15/8/00} takes medico-science to task on the issue of normalcy, demonstrating that 'disease' is ill-defined, whilst 'genetic disease' is effectively non-defined. After pointing to a finding that *"many physicians...equate difference with disease"* {op cit S2}, Caplan constructs an argument that, in practice, this is not strictly accurate: the definition of 'disease' depends more on subjective value-judgements about the desirability or otherwise of a detected 'difference', and such judgements vary with culture. Thus, for example, Caplan {op cit S4} cites an example of abortion following the finding of a chromosomal abnormality (XYY) which is not proven to have any physiological effect, but is *suspected* of being *possibly* a factor in criminality. Effectively, Caplan is discussing the medicalisation of social deviance, as judged from a particular standpoint which finds criminality abhorrent. The implications for eugenic practice are clear, but so also are those for disabled people: the role of 'nurture' - the social environment into which an individual is socialised - is diminished, as is any appreciation of the effects of social process leading to 'disability'. The equation appears to be that: disvalued difference = disease = disability.

It is in the light of this type of reasoning that Shakespeare {1995 p23} bases

his critique of the HGP on his forecast that

> *molecular biological imperialism would successively eliminate the*
> *insights of sociology, psychology* [and] *psycho-analysis... .*

If Shakespeare is correct, and he argues his case fluently as his paper progresses, then the influence of medico-science, and particularly genetic research and/or reductionism, marks a major attack on the foundations of Social Model theory, as the Medical Modellists seek to reassert their claims to diagnose and describe 'disability'. Given that, for mass society, medico-science represents, if not infallibility then authority, a major effect of genetic research may be to further the devaluation, arguably the disvaluation, of disabled people more generally. Once a condition has been labelled as a 'disease', society expects a search for a 'cure'.

A Model War?

It is *the* fundamental principle of disability activism that disabled people should not be defined in terms of their personal 'condition', 'difference' or 'impairment', a tenet which is traceable at least to Hunt {1966} and which recurs in all Social Model argument. The basis of the ongoing battle with Medical Model formulations is that, yes, impairment is 'real' (eg Morris {1991 p71}: *"I would still rather walk than not be able to walk"*), but it is by no means the be-all and end-all of a person's life. Impairment does not, or should not, provide the basis of a definition of a person as 'not normal'. The evidence above is that Medical Modelling, far from retreating from this position, has advanced it, to the extent that simply being found to be 'not normal' may of itself be deemed sufficient grounds to consider a person, or foetus, to be 'diseased' and facing a 'disvalued' life as a 'disabled' person. Western society, influenced and informed by medico-science, appears to be becoming more, rather than less, heterophobic with regard to people with impairments, at the same time as the definition of 'impairment' is widened.

Equally, for Social Modellists, the absence of 'normality' ought not lead to the

absence of human rights. The issue of 'rights' has been treated in some depth above, but there are very real fears expressed within the literature that disabled people as a group face a form of genocide, perhaps more correctly 'heterocide', which if substantiated would appear to be, on any analysis, a suspension of human rights. This is seen as stemming directly from their depersonalisation as a result of social processes fuelled by medico-scientific opinion and research. Such fears are clearly stated by Rock {1996}, as she develops a thesis that disabled people (her feminist approach focuses on women and girls) are denied basic human rights, including a right to life, pointing to compulsory sterilisation and abortion. The depersonalisation process is further evidenced, for Rock {op cit pps 121-2}, by Article 6 of a Council of Europe Convention on Bioethics, which allows for *"low* [not 'no'] *risk"* medical experimentation on *"incapacitated persons"*. It is, however, in the area of euthanasia that she is most provocative, claiming that older disabled people are, in effect, harvested of their body organs for transplant purposes. If Rock is correct, this would indicate the *dis*personalisation of at least some disabled people.

Notions of 'genocide' are supported by others, notably Wolfensberger {1994}, but are rarely taken to such extremes as Rock. Indeed, Shakespeare {1995} makes the point that there is now an organised and vocal disability movement to resist the worst excesses of medicalisation, although he does not belittle the task facing disabled people. Certainly, genetic research does not threaten the elimination of disabled people in general for, as Shakespeare {op cit} notes, much impairment is acquired, not congenital.

Ironically, what genetic research does threaten is the non-development of effective therapeutic regimes for specific conditions. This realisation stems from the idea that, as such genetic conditions are progressively eradicated by abortion or non-conception, pressure to cater for their effects decreases {Shakespeare 1995 p31}. Simultaneously, Shakespeare voices fears that parents who refuse to abort will come to be seen as irresponsible, and their offspring may be at increased risk of

stigmatisation, on the grounds that their perceived dependency could - should - have been avoided {ibid}. Thus at least some disabled people, for Shakespeare, face being further devalued - in fact disvalued - by society.

The reasoning of Shakespeare {1995} gives rise to a further avenue of exploration which does not appear to have been visited within the literature, and which the present author intends to examine empirically at a later date. Genetic research seems to have advanced at a pace far in excess of that forecast by even its most ardent supporters of the last decade. Consequently, Shakespeare {op cit p31} and others may have been overly pessimistic with opinions that gene therapy would not evolve,

certainly not in the short term, perhaps not for 50 years,

into viable treatments for genetic 'disorders', leading to a focus on abortion as the only means to combat discovered 'abnormality'. The possibility of effective non-fatal genetic intervention *in utero*, at least for certain conditions, now appears imminent.

Given that the Social Model seeks to sever links between person and 'condition', there are hard questions to be asked, and answers sought, about the stance to be adopted with regard to such genetic therapy. On the one hand, it may appear indefensible to demand that a child be born with a preventable impairment (recall Morris {1991} and her preference for the ability to walk, *even if society were fully accessible*). On the other hand, it may appear to people with that impairment that their personal status is undermined by such avertive therapy, and it would certainly seem that Shakespeare's comment on the likely effects on therapeutic regimes, and social status, for existing bearers of those conditions is pertinent. Whilst it is relatively straightforward to formulate a response, either for or against, to the destruction of people, the same cannot be said of the destruction of *impairment*. This is a much more ephemeral matter, and bears directly upon processes of social and self -identification and -valuation.

Conclusion

First and foremost, this paper has sought to demonstrate the breadth of literature available to inform research in the field of disability studies, and more particularly with relation to the social identity and relative values assigned to those who, for whatever reason, fail to measure up to society's expectations. In doing this, a range of disciplines has been sampled with the deliberate intention of highlighting the fact that, by restricting research to the 'standard' areas of sociology and social policy, there is a danger of overlooking theories with potential to provide powerful tools to assist a search for understanding.

In Section 1 it was seen that 'identity' is not an object, but a process. Further, there is good reason to believe that this process is dynamic - that it changes over time and from cultural base to cultural base. This goes some way to explaining seeming differences between those who hold firmly to the view that capitalist ideology is the engine driving the 'disabling' process and others who seek to appeal to a wider notion of 'culture'. Both are correct, in so far as they go, but the evidence adduced here indicates that neither go quite far enough. What is sought is a reconciliation between these unnecessarily opposing views, and it is suggested that the work of Lifton, when read alongside that of Hunt and Bauman (in Section 3), provides pointers to a clearer understanding of the processes in train. Only by understanding these processes will the possibility of being able to directly influence them, to guide them into different paths, be realised. Here Lifton offers insight into the effects of a perceived *"counterfeit existence"*, which brings an understanding of the rise of disability activism at a time when, ostensibly, standards of 'services' for disabled people had reached an historically high level.

Section 2, more conservative in its approach, sought initially to offer a 'Cook's Tour' of Ethics as applied to people with impairments, or to the unborn with some perceived flaw. The literature accessed there is standard in its field, and gives a clear

flavour of the thinking and debate in the area. Singer is featured, neither to vilify nor support his views, but merely because he states the options in clearer language than most. Whatever else he may or may not be, Singer is unequivocal. The latter part of this section drew comparisons between eugenics and genetics, noting several similarities in their approach to impairment. A common thread throughout the section was that a tendency of Utilitarian ethics, as seen in Singer's testimony and a review of both eugenic and genetic processes, is to depersonalise (and, it is argued here, potentially to *dis*personalise) disabled people. In this latter context it has been demonstrated here that the very essence of genetic and eugenic thought - the reductionist notion that the complex whole is determined by the simple part - derives from theories advanced in the mid nineteenth century. This simplistic (in whichever sense the reader wishes to assign) notion, as distinct from 'nuts and bolts' technology, has not noticeably advanced over the intervening years, arguably an indication of intellectual sterility or sclerosis. Meanwhile disability activism, building on foundations laid by feminist and black scholarship, has provided a fertile seedbed for ideas of social equality and of social process as the determinant in issues of group (and individual) identity.

In Section 3 Bauman introduces evidence of depersonalising (and, it is argued, *dis*personalising) tendencies within bureaucratic society, which may act against any stigmatised group, including disabled people. These tendencies, it is suggested, are similar to the 'Modernist' pressures claimed by Wolfensberger, which themselves are seen to link with the 'Narcissism' of Lasch. The idea is introduced that it may be appropriate to think of a 'Medico-bureaucratic Model' of disability, and further evidence of the alleged *dis*personalisation of disabled people is adduced from the work of Shakespeare and others.

Thus, in Section 3, the very real tension in this work is seen to centre on those two competing Models of disability, the Medical Model espoused by geneticists and eugenicists and the Social Model formulated and promoted by disability activists.

These two Models are incompatible - they have very different ethical bases, the former relying on Utilitarian 'greater good of the greater number' ideas, the latter intuitively adopting an Individual Rights perspective with which, seemingly paradoxically, to counter the individual- isation of the disability experience. There is no real paradox involved.

Only by asserting the right of an individual to be seen as a whole person, not as a constituent in some medical 'condition' or genetic 'aberration', can a convincing argument that society, not Nature or accident, creates 'disability' be advanced. This observation lies at the heart of the conflict over 'identity' between geneticists and disabled people: if disabled people are seen as people first, with all that that status confers in our society, then their identity may only be defined and redefined by social processes. If this identity is found to be defective, in that it does not accurately reflect the true value and worth of individuals as people, then society must accept the fault, and society may work to correct the process. If, on the other hand, people (disabled or not) are depicted as little more than machines assembled according to some 'genetic blueprint', then, in a crucial way, their identity is manufactured and may be manipulated by direct alteration of the engineer's plan - very 'Brave New World' - a situation which would absolve society from blame.

This latter point gives rise to a further avenue of exploration, flagged up in Section 3 for future investigation: 'Is it acceptable to use genetic techniques to eliminate specific conditions, but not people?', i.e. by applying 'corrective' genetic therapy to a foetus rather than the blunt instrument of selective abortion. Can this be said to devalue people with certain impairments, particularly in the context of an argument that people are individuals, not 'conditions'? There does not appear to be sufficient evidence within the literature, as yet, to adequately address these points in any way other than an empirical project.

ADDENDUM

Serendipitously, since this paper was written (in late August 2000), it appears from Press and Televison reports that a new phenomenon has appeared on the social scene, deriving from youth culture. This is a strong, indeed belligerent, reaction by young people to any notion that someone is *"dissing"* them, ie showing them *dis*respect. Whilst the relevance of such a development to the subject matter of this paper, and particularly Section 3 above, is self-evident, constraints of time have precluded the re-working necessary to include an appreciation of this nascent cultural notion of pejorative *"dissing"*.

Although youth culture is notoriously transient, this may well present a rallying-cry for people with impairments who, it has been claimed above, are subject to multiple "*dissing*":- *dis*crimination, *dis*valuation and *dis*personal- isation, arguably due in part to society's fear of *dis*ease. The Social Model of Disability is clear that the sum total of these *"dissing"* processes is the *dis*ablement of people with impairments, whilst the implicit thrust of disability activist argument, and of this paper, is that ultimately *dis*abled people are *dis*- respected by society: they are accorded neither the rights nor respect routinely granted to 'normal' citizens.

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