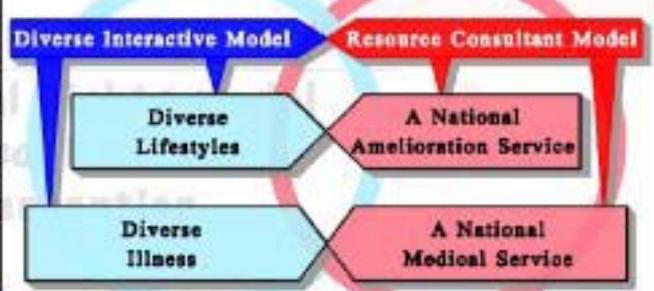


# The classic model of disability and intervention

# The social model of disability and intervention

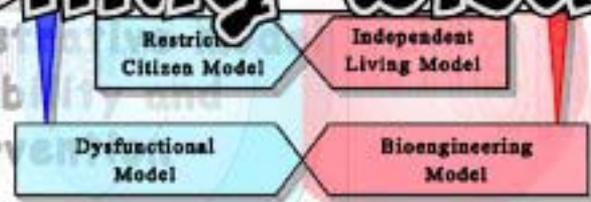
## Interactive diversity in lifestyles model



"an aspirational" culture

# Modelling Disability

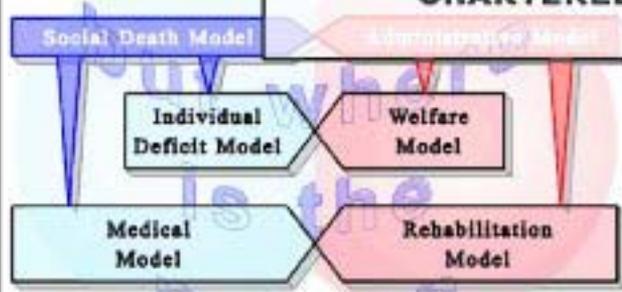
## The administration of disability intervention



"an equal opportunities" culture

"a person centred" culture

## Independent but Insecure in the CHARTERED STATE



"a healthy living" culture

"a cradle to grave" culture

## Dependent and secure in the WELFARE STATE

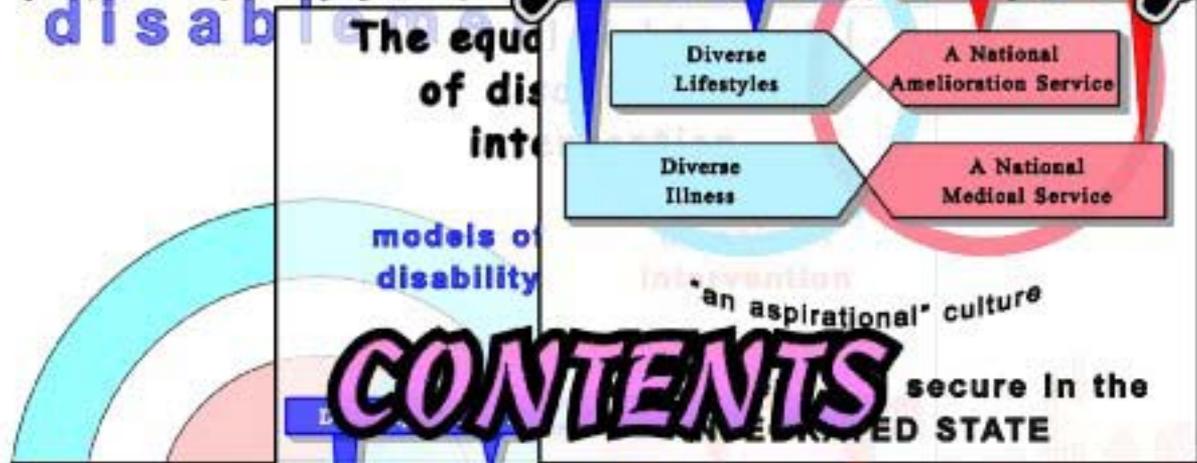
care

The classic model of disability and intervention

The social model of disability and intervention

Interactive diversity in lifestyles model

# Modelling Disability



## CONTENTS

- 1 Who Needs Models of Disability?
- 2 The Modelling Kit
- 3 Yesterday's Model
- 4 Today's Model
- 5 Tomorrow's Model
- 6 Finishing Touches



care

# MODELLING DISABILITY

*Vic Finkelstein*

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This kit is based on a presentation at the workshop organised for the 'Breaking The Moulds' conference, Dunfermline, Scotland. 16-17 May 1996

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## 1 Who Needs Models of Disability?

*'Spoon feeding in the long run teaches us nothing but the shape of the spoon.'*  
(E. M. Forster, *The Observer*, 7 October 1951).

The social interpretation of disability emerged in the early 1970s during the combined struggles of disabled people living in residential institutions and the community. At that time this view was made public in *Fundamental Principles of Disability* by *The Union of the Physically Impaired Against Segregation* in 1976, as well as in media presentations and popular articles by members of the Union. The focus was on strengthening the spontaneous demands of disabled people for full integration into all aspects of mainstream social life. We were, however, careful to explain that 'integration' was not the same as 'assimilation'. Interpreting 'disability' as being caused by the way society is organised for able-bodied living helped us oppose the argument put forward by some social policy academics that our needs could best be met by increased state benefits, sheltered employment, special education and special housing, etc. These measures, they believed, could 'compensate' for the 'disabilities' that we unfortunately have to suffer. There was no awareness that their approach actually helped keep us permanently dependent on services run by people with abilities and state hand-outs. Some years later the social *interpretation* of disability was developed and explained by Mike Oliver, a disabled academic, as a 'social *model* of disability'. The social model helped spread the idea that it is the way society is organised that is disabling. In *this* guise the social interpretation of disability undermined the confidence of 'experts' with abilities who traditionally maintained our plight was due to our impairments and helped challenge their power over our lives. In time, however, in the hands of a new and growing disabled elite teaching and presenting the model at conferences, workshops and training sessions, the social model of disability progressively degenerated into a sterile prescription for 'explaining' our situation. There is an urgent need for the grassroots to regain its control over the social interpretation of disability because it is only here that the radical agenda can be returned to our struggle for emancipation.

Nowadays many people have come to think of the 'social model of disability' as if it explains our situation. Hard, perhaps, to accept but models do not *explain* anything. Models should not be confused with theories or hypothesis, which *do* attempt to reveal the inner, or hidden, laws governing the nature of things and relationships. Models, on the other hand, work best when they are used as tools to give us insight into situations which otherwise are difficult to *begin* explaining. We construct models because without them we may remain unable to detach ourselves from a fruitless way of interpreting a situation or problem. Building a model airplane, for example, which is then subject to tests in a wind tunnel can help in the planning of real aircraft by revealing how new design features might actually function in different circumstances. Children spontaneously play with models, such as toy houses and construction kits, because there is natural pleasure in gaining insight into the world in which they live. The value of such models are revealed when the lessons learnt from their use are put to the test in real adult life situations. Models, then, are neither explanations of events nor

are they prescriptions for action. They are merely tools for gaining insight into an existing stubborn problem so that the future may be changed.

It is essential that the social interpretation of disability, which was thought-up by 'ordinary' disabled people, is reclaimed by the grassroots before it is only disabled academics and researchers who can understand and present their *rectified* version of the social model of disability. While this conveniently keeps the elite employed and earns rewards from politicians with abilities the mass of disabled people continue to be denied access to an important weapon for changing the lives of *everyone* living in the disabling society.

This modelling kit is provided as an example of how different components of 'disablement' can be taken apart and then put together again in new ways, together with new pieces, so that sense can be made of what *we* might want to change and where *we* may hope to see society going. As an *illustration* I hope it encourages others to join in the creative fun of making their own disability models, always bearing in mind that the purpose is to help us change the disabling society.

In putting together my latest disability model I have:

- firstly, tried to identify key 'disability' elements that have appeared at different historical periods;
- secondly, selected those elements which I feel should be included in the final model;
- thirdly, invented new components when these seem to be wanted; and
- fourthly, put the selected pieces together again to make what I think could really be *the* 'social model of disability'.

The whole exercise is something like fitting together the pieces of a giant jigsaw puzzle. Each element, part or piece of the total 'disablement' picture is cut-out for individual manipulation in constructing the model. Alongside each of these pieces I have tried to describe it's shape and colour, and then why it is 'glued' into a particular slot. Such guidelines, after all, are what you would expect to find in a modelling kit!

Finally, remember people with abilities have been so obsessed throughout history trying to be 'super-human' that it is now only disabled people who can teach them what it means to be really 'human'. A social model of disability which does not reveal, highlight and explore this fundamental truism will only become yet another version of the special way people with abilities end up labelling us.

## 2 The Modelling Kit

*'The greater our knowledge increases the more our ignorance unfolds.'*  
(John Fitzgerald Kennedy, Speech, 12 September 1962).

disablement

I want to start our consideration of different interpretations of disability and the cultural context in which these are formed by firstly identifying what seem to be the agreed key components. These all fall under the general heading of **disablement**. This is a global term which is meant to include all the physical and mental aspects of both disability and impairment, as well as the personal and social components. In other words, I will start with a global view that seems to incorporate all the basic elements which contribute to the common meaning of disability. This will also place a marker on the point of departure for the more recent interpretations of disability.

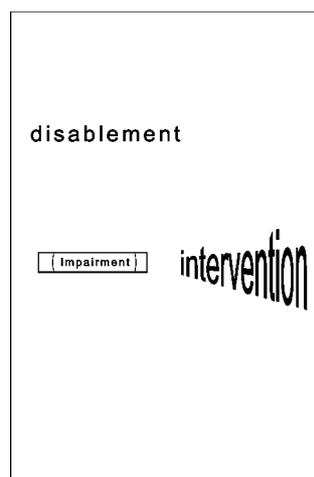
The first, and primary, element recognised by just about everyone who is disabled or who works with disabled people is the presence of **impairment**. Despite this consensus there may be disagreement about the range and degree of defects or deficits that can be counted as 'impairments' which are relevant to disablement. Should hidden or not immediately observable impairments, for example, epilepsy and heart conditions, be included? Should

disablement

{ Impairment }

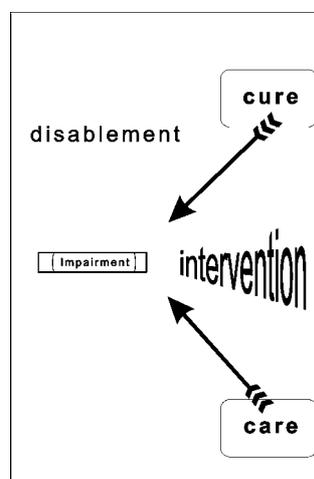
both mental and physical impairments, such as mental illness, learning disability and auditory impairment be counted? What degree of impairment is significant before a person may become identified as disabled? Is short-sightedness easily corrected by glasses, for example, relevant in the identification of disabled people? How stable does an impairment need to be before it is identified as 'chronic illness'? Are cerebral palsy and muscular dystrophy equally relevant to disability or does the latter fall more appropriately into the field of illness and medicine?

Despite these questions it seems to me that in the vast majority of situations there is usually very little difficulty in including or excluding a particular impairment under the general term 'disablement'. Impairment, then, is the first aspect of a person that is noticed when the issue of disablement is raised. In the first instance this may be a midwife detecting an impairment in a newborn baby, or a parent noticing how a toddler is beginning to walk, or a teacher concerned about a pupil having difficulty reading, or a GP examining a patient. In nearly all situations where disablement is identified, then, it is the impairment that is the first concern and becomes the focus of attention.



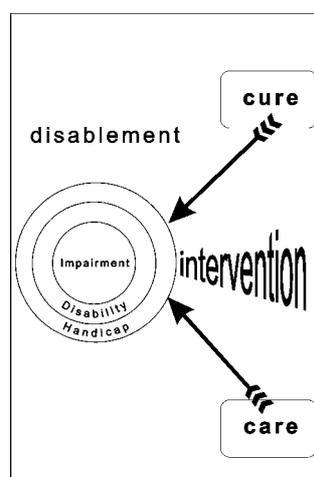
Once an impairment is identified and concern raised, rightly or wrongly about its significance in affecting the person's future quality of life, then the impairment becomes the pre-eminent focus of attention for various forms of **intervention**. The need to intervene following the identification of an impairment has been the commonly accepted reaction to the presence of mental or physical defects or deficits, or expected deviation from the norms in functioning and behaviour. It is only relatively recently that this response to 'abnormality' has been vigorously questioned in the world of disablement.

Historically the first consideration for interventions concerned with disablement is how to **cure** the impairment. This means that medical interventions assume a primary role, either by dealing with an infection if this is the source of the impairment, or through surgical interventions if the defect can be removed or modified by this method. Secondary to this, various therapies may be introduced, such as physiotherapy or psychotherapy, as a supplementary route to a cure. If this is not directly successful then the defect or deficit may at least be reduced to the point where it is relatively cured (for example, improving strength in a specific limb muscle so that the function of that limb can return to normality).



While personal equipment, like glasses, do not cure an impairment this approach may render the impairment so inconsequential that it can be regarded as cured. It is only when there are no more cure options that the need to **care** logically follows the medical interventions. In this sequence, however, care is only prescribed in the light of an intractable medical problem. The 'cure or care' approach to intervention is perhaps the most basic response within the field of disablement. The significant relationship, illustrated in this diagram, is that interventions are targeted, or zoom-in, on the impairment. All attention, is in this direction, focused inward towards the impairment.

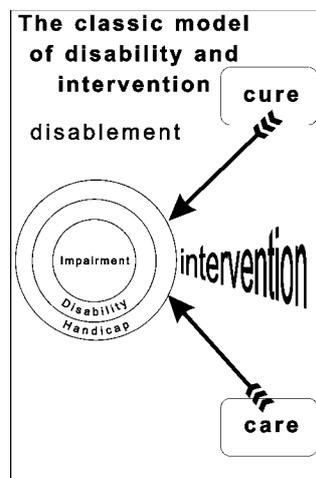
The significant relationship, illustrated in this diagram, is that interventions are targeted, or zoom-in, on the impairment. All attention, is in this direction, focused inward towards the impairment.



With all this concentrated medical and para-medical attention on impairment it is not difficult to see how **disability** and **handicap** naturally emerge as further targets or categories for intervention. Para-medical interventions, such as physiotherapy and occupational therapy, to *cure* dysfunction resulting from impairment are the logical outcome of limitations in medical intervention to cure the impairment. Similarly once the functional or behavioural deviations from the normal are judged stable and there is no cure then *care* may be prescribed to cure the assumed social consequences of impairment and disability. It may seem curious that 'care' can be *prescribed* to 'cure' social dysfunction but in my view the medicalisation of all interventions is one of the consequences of the medical dominance established during the

natural primary concern with impairment.

The configuration between ‘cure or care’ interventions and their focus on impairment, disability and handicap illustrated in this diagram appears to be the inherent legacy of a long history in the making of disablement. My argument, then, is that by the late 1940s all the

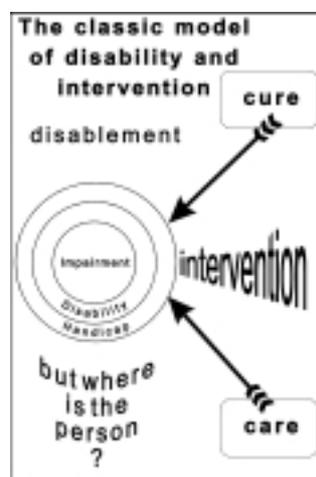


elements for a **classic model of disability and intervention** were in place and so well established that no one questioned the scientific basis for this approach to disablement.

All intervention arrows pointed at a target with impairment in the centre and handicap in the outer ring. The multi-coloured target evolved *inside-out* in parallel with the emergence of a variety of interventionists, the Helping Professions Allied to Medicine (PACs), each of whom aimed at their own particular colour. By the 1950s all that remained for the profession that had naturally originated this model was to orchestrate the growing diversity of interventions by demanding teamwork under their direction. It is no accident then, in my view, that for the next four decades *rehabilitation* became the framework for supporting the

impairment, disability and handicap target that had been created by medical dominance over disablement. It is also no accident that the route to understanding disability in the classical model is shaped by the ‘case history’ (or biographical) approach with its *inside-out* reflection on the personal experience of disability.

The single most important insight revealed in these illustrations, I hope, is that building a framework for understanding and intervening in disablement on the basis of a medical focus



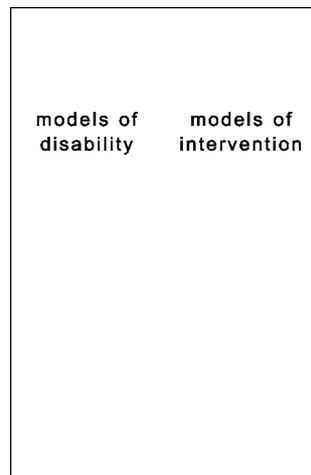
on impairment results in the disabled person dissolving into a series of problems. The medical view that disablement involves ‘chronic morbidity’ posing an ideological challenge, even a crisis, for health care in ‘modern’ society has lost sight of the fact that it is human beings who are being transformed into targets. **Where**, we may ask, **is the person** in the classic model of disability?

I do not believe that the *holistic* approach to rehabilitation can resolve this question. This is simply because the need to stitch the disabled person together into a patchwork of health care problems for teams of helpers to deal with is itself a product of the mistaken way that medical concentration on impairment has set up disablement as a target in the field of *health*. As I shall suggest later this is quite simply the wrong field for building an appropriate

model to guide intervention strategies for disabled people, but for now we need to look more closely at the classic model of disability.

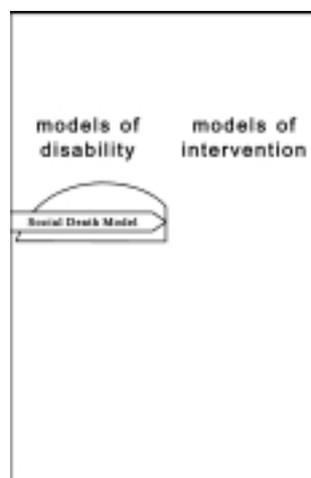
### 3 Yesterday's Model

*'It is unnecessary – perhaps dangerous – in medicine to be too clever.'*  
(Sir Robert Hutchison, Lancet, 2:61, 1938).



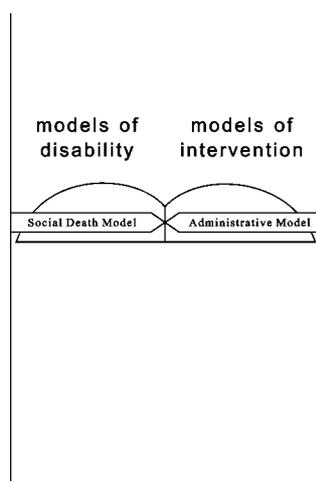
It should be clear from my interpretation of the 'classic model' that the issue of disablement arises at the same time that impairment is identified as a target of concern and that this triggers an immediate firing of interventions. This in turn sets the scene for the entrenchment of two distinctive sides within the global setting of disablement. On the one side there is impairment, disability and handicap (attached to the individual of course), and on the other side the range of interventions responding to cure or care intentions (invented by people with abilities of course). It is useful, I believe to expand our discussion by seeing these two sides in terms of two models - **models of disability** and **models of intervention**.

The link between impairment and the need for intervention is a powerful reinforcer of the common view that to be disabled is to be unable to function without the assistance of others. Social independence, then, is seen as a special problem for disabled people and the required interventions are interpreted as quite separate from mainstream facilities and utilities that people with abilities use. These facilities, used by people with abilities, are regarded as an integral and necessary part of the social world whereas those used by disabled people are not only separated from the mainstream but regarded as *special* because they provide an alternative to integrating into mainstream society. The 'invacar' for example, was provided as an alternative to accessible public transport, and the goal of special education was hardly related to preparation for a working life in ordinary employment. Well into the late 1960s disabled people were not seen in ordinary places of employment, education and leisure facilities as well as being absent from public transport and the main communications media (except as tragic cases). Charities, of course, have been well researched for their contribution to the general cultural view that disabled people are socially dysfunctional. This separation between disabled people and their non-disabled peers can be interpreted as part of a historical process that transformed disabled people into non-social beings (they are simply not participants in the common social world). From this point of view becoming disabled can be regarded as being sentenced to social death.



Ultimately, the final expression of this social death is in the total removal of disabled people from society by placing them into residential accommodation. In the words of the notorious research by Miller and Gwynne (1972) p.89: 'by the very fact of committing people to institutions of this type, society is defining them as, in effect, socially dead, then the essential task to be carried out is to help the inmates make their transition from social death to physical death'. Miller, E.J. and Gwynne, G.V. (1972) 'A life apart'. London: Tavistock Publications. It is in this context of systematic segregation that I regard the **social death model** as the first historical model of disability.

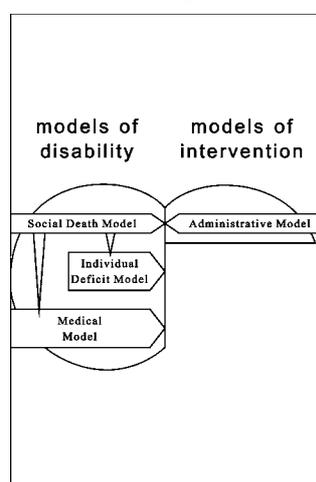
Once the impairment is interpreted as having rendered the individual socially dead (I, like countless others, heard one parent saying to another that my life was ruined after my accident)



then it is clear that cure or care interventions have to be prescribed for the disabled person (since they are now considered functionally incapable of managing their own lives). Interventions are targeted towards the passive disabled person by others. This implies a degree of expertise on the side of helpers and a degree of dependency on the side of those being assisted. In other words the helpers, practitioners, professionals or voluntary workers, administer the chosen intervention that they consider appropriate to the individual's impairment, or disability or handicap. It matters little which particular group of helpers administer to the needs of the disabled individual being assessed and helped, although as I mentioned earlier, I believe the pre-eminent role that the medical profession has had in addressing the problems of impairment has

enabled their domination over all forms of intervention and given them the principal administrative role. In my view, then, the first historical model of intervention is the **administrative model**.

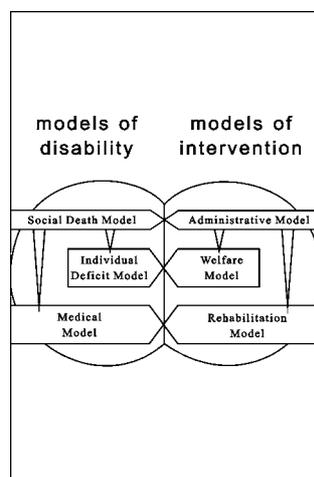
Once an individual is labelled disabled then the social death model of disability encourages interventionists to split their concern about the individual into two problem areas - *welfare* and *health*. This gives rise to two sub-models, the **individual deficit model** and the **medical model**.



In the former disabled people are interpreted as unable to carry out their activities of daily living because of the deficits which they possess. The degree of the impairment, whether static or progressive, etc., will be considered significant in determining the level of social competence that is thought possible. However, the important factor, in the individual deficit model, is the belief that it is the impairment (which is permanent in disability) causes the continuing inability of the individual to function normally. It is in this sense that people who have impairments are generally regarded as 'disabled'.

In the medical sub-model of the social death model of disability life-long health problems are assumed to result from the possession of a permanent impairment. While the nature and degree of the impairment is significant in influencing the diagnosis between illness and disability what is important in the medical model is the view that an impairment causes continuing health problems. This is why the World Health Organisation (WHO) considers 'disability' as falling within their mandate. As can be seen from my drawing of this model's components, I do not agree that a simple 'medical model' of disability, on its own, can fully represent what has been the *traditional* overall interpretation of disablement.

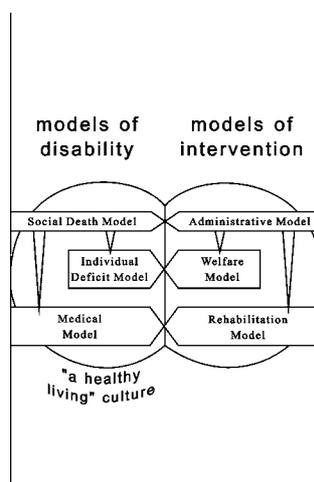
When we look at ‘interventions’ in relation to the ‘individual deficit’ and ‘medical models’ of disability the two areas in which disabled people are thought to face problems are *health* and *welfare*. Construed as individuals with permanent deficits disabled people have been considered unable to function independently in, for example, education, employment, and



leisure pursuits. This leads to the characterisation of disabled people as socially deviant, deprived, marginalised, vulnerable, special, etc., and raises the need for the administration of compensatory welfare (‘care’) to meet these concerns. Logically, then, the ‘individual deficit’ model of disability is counter-balanced by a **welfare model** of intervention. On the health side the isolation of disabled people from mainstream life has meant that even in the area of health provision disabled people are diverted into *special* services. Since impairment is permanent in disablement it is logical for the medical profession to acknowledge its inability to ‘cure’ and promote instead those interventions which can best approximate to the ideal of ‘normality’. This has found its perfect expression in the **rehabilitation model** for guiding interventions. While there is a

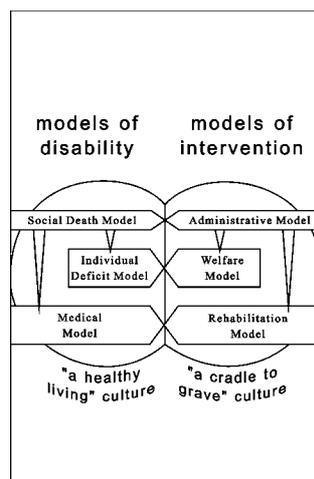
sense in which all medical practice is rehabilitative in intent, the development of the rehabilitation specialism explicitly for the treatment of disabled people in the health service context is a significant reminder of just how isolated disabled people are from all mainstream statutory and voluntary provision.

The ‘social death’ model of disability, with its two sub-models, the ‘individual deficit’ and the ‘medical’ models, can be regarded as an expression of a **healthy living culture**. In cultural



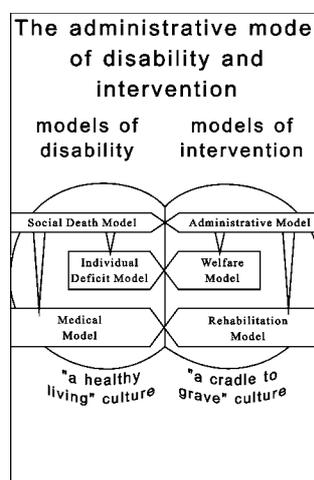
terms, disability is seen as a health issue and any impending appearance of impairment, such as in the newborn baby or the increasing numbers of older people who are disabled, is considered a threatening health crisis. The healthy living culture creates a particular identity strain on disabled people. Media presentations extol the *body perfect* ideal for us all and charities are faced with the dilemma of how to present disabled people in their appeals: positive images are hardly likely to generate the non-disabled public’s sympathy for fund raising and negative images reinforce the hopelessness of the cause as well as generating rejection by the very disabled people they are supposed to help. Disabled children are confronted with confusing role models where disabled adults are hardly regarded as the ideal. Concerned parents with abilities (who

may well be looking for alternative approaches to achieve *normality*, such as the Peto method), and health professionals often see disabled lifestyles in terms of problems in promoting healthy living. The *prevention* of disability very easily becomes the global catch-phrase for this cultural approach to disability and, of course, euthanasia becomes increasingly significant within this culture.



Administering services to disabled people because they are incapable of *normal* personal and social functioning is an important component of a **cradle to grave** cultural approach to interventions concerned with disability. By this I mean that disabled people are regarded as having a life-long need for assistance from others, to compensate for their individual deficits at the social level or to rehabilitate functioning at the medical level, in order for them to survive and live to their maximum potential in a world designed for people with abilities. Within this culture disabled people are always viewed as *vulnerable people* (people at risk) and judgements about our quality of life, and interventions in our lifestyles, by just about everyone is both accepted and legitimate.

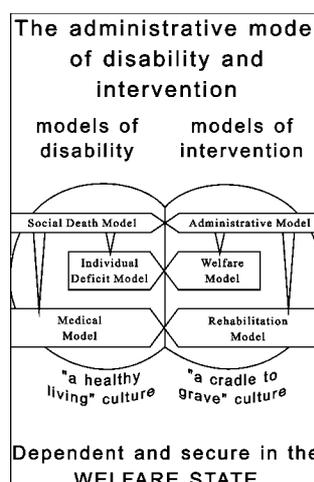
The model is now complete. In my view when the 'classic model' is used as a template to define the situation of disabled people and identify appropriate forms of intervention **the administrative model of disability and intervention** to disablement emerges as the overall



model after the Second World War. As mentioned earlier, the medical profession usually becomes involved in dealing with impairment when this is first identified. This advantage, in the market to intervene in the lives of disabled people, has facilitated the medical profession's domination over the administration of services and justified their definitions of disability. I believe this is why the medical model is often thought of as one of only *two* models of disability (the other being the social model). There is no reason, however, why social administrators or lawyers should not assume the dominant role if administering to the needs of disabled people is informed by care in the community or the enforcement of civil rights law. What is important is not *which* profession is dominant but that disabled people are marginalised in their own affairs as *others*

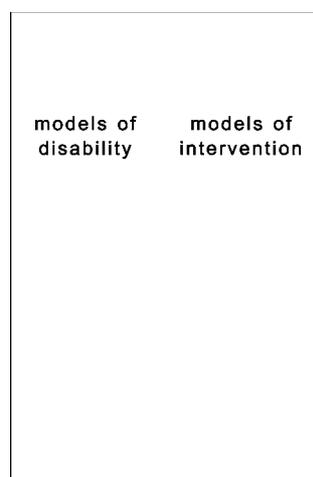
administer to their needs on their behalf because, one way or another, disabled people are regarded as incapable of doing this comprehensively for themselves.

It is when we look at the administrative model of disability in detail that the 'healthy living' and 'cradle to grave' cultures draw our attention. Since these also provide the cultural context for the construction of the Welfare State it seems clear that what happens in the world of disablement is integrally connected with what happens in mainstream society. The administrative model of disability is created within a national culture that idealises healthy living and willingly succumbs to cradle to grave interventions when this health ideal is thought to be in jeopardy. This means that the whole population has a life-long dependency upon others for their well-being and not only disabled people. We can interpret this as meaning that everyone is both **dependent and secure in the welfare state**. What seems to be a unique characteristic of disabled people turns out to be a mirror of the general *state*, only different in degree. Perhaps, then, what disabled people dislike about their dependency in the Welfare State can also expose intrinsic problems in this approach to health and welfare for mainstream society.

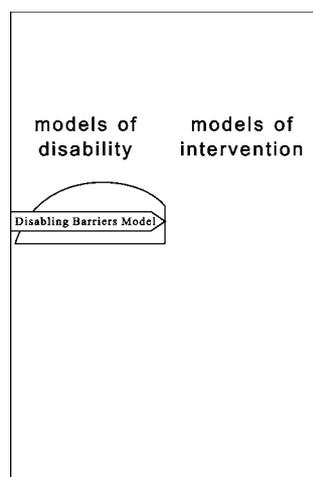


## 4 Today's Model

*'There was never an age in which useless knowledge was more important than in our own'*  
(Cyril Joad, The Observer, 30 September 1951).

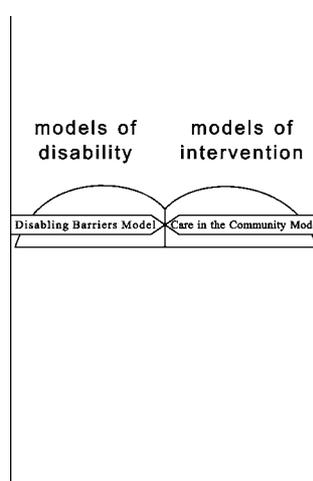


The provocative question for us at the dawn of the 21<sup>st</sup> Century, in my view, is not 'Why the Welfare State is being dismantled?' but 'Why has there been so little resistance?' Understanding general disillusion with the 'healthy living' and 'cradle to grave' cultures that fed the growth of the Welfare State could provide insight into why disabled users of the health and welfare services are now looking for alternative support systems. The emerging **models of disability** and **models of intervention** which place citizenship *rights* and *equal opportunities* much more central to the way 'disability' and 'support' services are provided sets the framework for our discussion.



In an approach to disability where all people are regarded as equal, problems in personal achievement are attributed to social and personal barriers that restrict, or disable, their potential rather than to the limitations imposed by their deficits. This, I have called the **disabling barriers model** of disability. In this model disabled people are not stereotyped as individuals who are unable to function, who deviate from the normal, or who naturally have a poor quality of life, but they are accepted as citizens who are *prevented* from realising their personal and civil rights that are supposed to be common to all people.

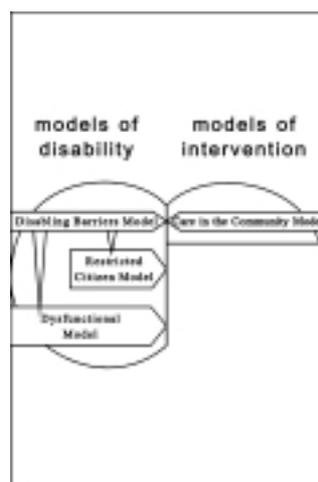
move more decisively onto concerns about enabling disabled people to *live* in the community rather than, as at best hitherto, simply to *be* in the community. While the quality and degree of



help that can be provided in overcoming barriers may vary considerably, I believe the significance of the **care in the community model** of interventions is its tendency towards the provision of assistance within mainstream society. This has created a new door to greater self-help involvement in service development. The organised disability movement has been looking for this opening since the late 1960s when the social interpretation of disability began to emerge out of the struggles against the administrative control that was exercised over disabled people in the 'healthy living' and 'cradle to grave' cultures of the crumbling Welfare State. With more than two decades to develop a deeper understanding of the barriers approach to disability and increasing opportunities to gain practical experience in their own organisations, disabled people are now pushing open the self-help

door to service development.

There are two obvious sub-models when we look at the way disabling barriers impact on the *welfare* and *health* rights of disabled people. These I have called the **restricted citizen model** and the **dysfunctional model**. In the former model of disability it is accepted that disabled people should be treated as *equal citizens*. Therefore, although impaired quality of life may be assumed, this should not detract from their access to all the general rights and duties that are accepted as part of citizenship. This approach parts company with the ‘administrative model’ of disability as well as the various World Health Organisation’s (WHO) interpretations, which target on the impairment as the starting point for identifying resulting personal and social problems. The ‘restricted citizen’ model starts with the positive view that disabled people have no intrinsic impediment to their independent rights. In this



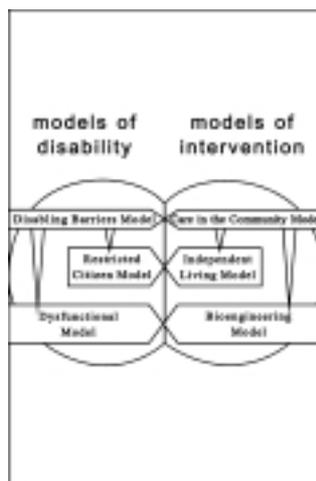
model disabled people’s citizenship rights are restricted by the environmental and social barriers that have evolved over the centuries as people with abilities moulded and adapted the world according to their own idealised *normal* attributes.

In the ‘dysfunctional’ sub-model defects or loss of function are recognised as components of disablement. However, these impairments are regarded as purely personal – that is, while they do involve the possession of deficits of the body or mind, these are *not also* regarded as social deficits or *causing* any social dysfunction. For example, a person may not be able to move or control the movement of a limb but this does not imply social immobility; a person may not be able to hear but this does not imply an inability to communicate. In other words, adoption of the disabling barriers model with its emphasis on citizenship rights leads to a separate

consideration of health rights. This is especially significant for people who are restricted by disabling barriers because it increasingly divides social interpretations of dysfunction from explanations of personal dysfunction (*welfare* and *health* concerns). This division happens despite the consistent efforts of the ‘caring’ professions to maintain their historic ‘holistic’ control over the definition and interpretation of disability. Some disabled people have also been promoting a *rectified* social model of disability in which ‘impairment’ is once again included in the meaning of ‘disability’. This return to a close bond between social and personal dysfunction (maintained in the medical and administrative models of disability), however, cannot resolve the heightened tension between the social and personal raised in the barriers model of disability.

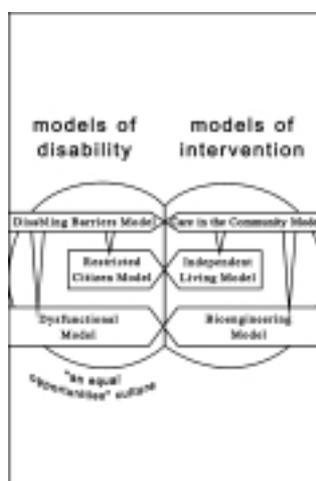
With *restricted citizenship* in mind as the *welfare* sub-model concern of disability, intervention has become more community orientated and concerned with ‘rights’ which can facilitate equal opportunities for disabled individuals. Equal opportunities here, of course, means an equal opportunity to compete in the market system alongside non-disabled individuals for scholastic achievement, employment, financial gain, social status, and so on. *Interventions*, then, are aimed at controlling the way disabled people enter or conform to the needs of the market created by people with abilities. In countries which have a Constitution ‘rights’ are normalised by this document. In the UK where there is no formal constitution, however, ‘charters’ have been introduced to regulate people’s cultural expectation of their rights. These clusters of charters are aimed at facilitating a viable independent existence within the global production and purchasing economy. Statutory and voluntary service providers have responded to this development (in parallel with the decline in the global ‘administrative model’ for servicing disabled people) by establishing *Community Care* services and *Independent Living Centres* (ILCs). Organisations of disabled people have set up *Centres for Independent Living* (CILs). Whatever it thinks of itself the growing disabled

people's 'civil rights' and 'independent living' movement, therefore, nicely conforms to the structural changes that are controlled by people with abilities as the regulated 'free' market increasingly replaces the 'dependency' creating health and Welfare State. It is in this context that an **independent living model** offers an obvious, if deceptive, guide for developing social services for disabled people. In this arrangement the significance of certain professions, especially care managers and lawyers, is increased; the influence of medicine and the professions allied to medicine (PAMs) naturally declines (not without a struggle to *revitalise* professionalism of course!). An interpretation of the social model of disability then, which puts 'rights' at the forefront of importance in attaining independent living, merely harmonises (rectifies) disabled peoples' consciousness with the 'legal rights' and 'care' professions' as their importance increases in our lives. The concept of 'independent living' is not only compatible with 'care in the community' but an important appendix to the modernised disability-related forms of intervention.



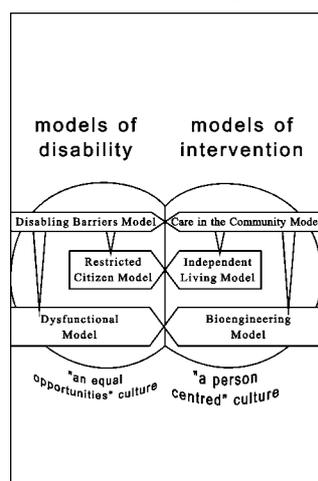
As intervention shifts from 'welfare' to 'independent living', in parallel with the declining Welfare State, 'rehabilitation' as the preferred model for servicing the medical model of disability has lost much of its glamour. Attempts to salvage 'rehabilitation' by moving it into the community, as 'community-based rehabilitation', has noticeably failed to meet the onslaught of expanding 'care in the community' services in industrialised economies. Even where community-based rehabilitation has gained some popular support this is often by merging it with the more viable independent living services. In this case rehabilitation moves even further away from its 'medical' origins in the *health* service bundle of interventions. Rehabilitation cannot survive as the preferred model for intervention in the community associated with the new dysfunctional model of disability. The declining significance of rehabilitation in the collapsing Welfare State has raised the status of the other core physical intervention components associated with the dysfunctional model of disability – surgery, genetics (including euthanasia), bioengineering. From this perspective dealing with dysfunction is best serviced by increasing the disabled individual's *right of access* to interventions which may help transform her or him into an 'ideal' person with abilities. This I have called the **bioengineering model** for intervention.

It seems sensible to interpret the 'disabling barriers' model of disability, with its two sub-models, the 'restricted citizen' and the 'dysfunctional' models, as elements of **an equal opportunities culture**. This changing culture is the result of modernising the former 'healthy living' culture. In this context, then, 'disability' comes to be seen as meaning unnecessary restrictions to opportunities within the global market system. They are interpreted as *unnecessary restrictions* because the social and personal barriers to functioning may be removed by the appropriate service interventions. The right to these services is mediated by civil rights law. In this cultural climate there is little restraint on the mass media's worship of science as providing everyone with an opportunity (ultimately) to participate equally in the market system. The new culture is glib and shallow but nevertheless raises expectations that were previously suppressed in disabled people by the dependency-creating over-emphasis on the narrow 'healthy living' culture with its medical bias. In the



new cultural canon even ‘charity’ becomes concerned with the provision of aids to daily living rather than incarceration in residential homes. The ‘equal opportunities’ culture, like the ‘healthy living’ culture, encourages foolish illusions about the possibilities of *including* disabled people into a society designed by and for people with abilities. No accident, then, that ‘inclusive’ has become the catchword in place of the term ‘integration’.

The characteristic feature of the ‘independent living’ and ‘bioengineering’ service sub-models, of the ‘community care’ model, is that interventions are principally concerned with supporting

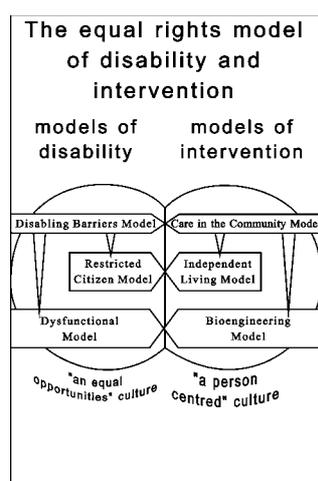


the disabled individual attain self-sufficiency, autonomy, physical perfection, competitive skills, etcetera, alongside people with abilities. Individual success in sport is elevated to a high achievement status. In this new disability model, then, intervention services maintain their focus on the individual, but citizen participation replaces the passivity that was expected from the population dependent upon ‘cradle to grave’ services. In this climate, then, **a person centred culture** emerges. The independent ‘consumer’ living in the community, purchasing every kind of commodity or aid, attending spectator sport and entertainment events, submitting to interventions which create or give the impression of physical perfection, and reinforced by rights embellished in law, becomes the beacon (the ideal) in the new

culture. It is in this context that being a disabled person starts to be viewed as less of a social disaster than hitherto. This certainly helps offset the overwhelming dependency-creating services that disabled people were expected to need.

All the components of the new model are now in place.

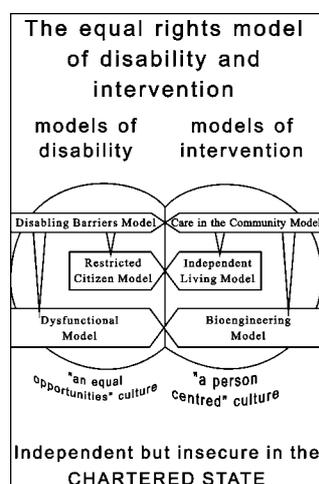
Now we have all the main elements of the dominant disability model that appears to have emerged as the collapsing ‘administrative model’, mediated by the National Health and Social



Services, gathered momentum and gave birth to new services. This complex model I have called **the equal rights model of disability and intervention**. In my view important elements in defining disability and providing services are retained from the earlier dominant model, such as ensuring services we use dovetail into the statutory service patterns set by people with abilities. However, our ‘rightful’ presence in the local community, as disabled people, is more accepted (at least until bioengineering finds a solution). ‘Equal rights’ encourage disabled people to assert their individuality and the legitimacy of diverse needs within a multi-cultural society while at the same time promoting integration into the non-disabled world. Willingness to accept our right to be responsible for ourselves is a very significant advance in our history but the price is acceptance of an over-arching cultural emphasis on competition

between people and the ever present threat of splendid isolation (independence). Can disabled people compete with non-disabled peers when only the latter set the rules for competition?

In the 'equal rights model of disability and intervention' independence is the supreme goal and insecurity the price. However, pursuing personal independence, to any excessive length in a climate of social insecurity, is bound to increase personal selfishness in the national culture. The long-term consequence is an avaricious and 'uncaring' population. To counterbalance



this social 'law' has to be respected and a plethora of regulations, standards, rules, codes of practice, league tables and, of course, *charters* have been put in place. We can characterise the situation of disabled people in this new society, therefore, as being **independent but insecure in the chartered state.**

This shift in emphasis is wonderfully captured in the focus of campaign slogans used within the disability movement. *The Union of the Physically Impaired Against Segregation* leaflet of the middle 1970s entitled 'Jobs not Charity', for example, has changed to 'Rights not Charity' in the publicity used by the *British Council of Disabled People* in the 1990s!

Disabled people have moved a long way in challenging the previous 'administrative model' which dominated definitions of disability and the provision of services which we use. On the other hand, our publications, literature and conferences, which should provide grassroots activists with tools for clarifying our route to emancipation, have increasingly become communications media for disseminating no more than the growing disability elite's reactions to current events controlled by people with abilities. In these circumstances an 'equal rights' model of disability for promoting disabled people's inclusion in the Chartered State should not be confused with *the* 'social model' of disability. In my view it is only by *rectifying* the original radical 'social model of disability' that makes it possible to obtain grass-roots support for the illusions taught by the elite under the banner of equal rights in the Chartered State.

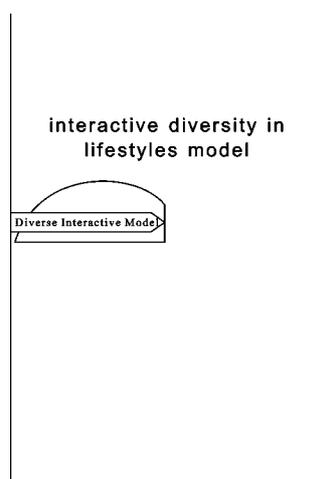
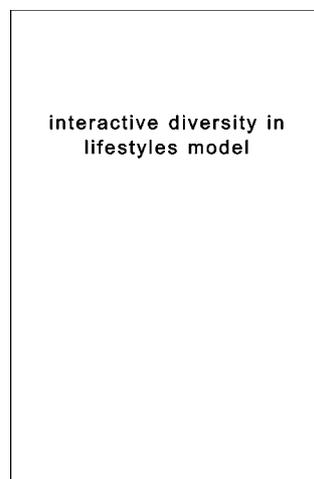
There is a salutary lesson in the much admired *Americans with Disabilities Act of 1990*. It is well to remember that the campaign for this legislation took place in the absence of a social model of disability (in the British sense). It is no accident, therefore, that the medical expression 'people with disabilities' is the preferred USA term for our identity. What this tells us is that the struggle for civil rights is not necessarily informed by the social model of disability.

## 5 TOMORROW'S MODEL

*'An expert is one who knows more and more about less and less.'*

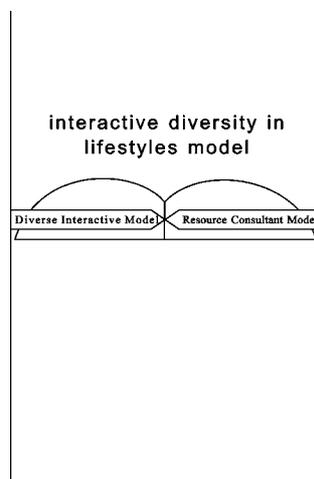
(Nicholas Murray Butler, Speech).

It is only when we think of a 'model' as a tool, and begin using it to imagine something new that we would like to create, rather than just as a way of labelling the present or the past, that models really become useful. While not ignoring the great deal of thought that has gone into developing the health and welfare services put in place by the 'welfare' and 'chartered' states we should be careful about accepting an existing context for a new disability model simply because one already exists. With this in mind the first task in constructing a new model, in my view, is to avoid the artificial separation between our living situation (models of disability) and what support we need (models of intervention). Such divisions become necessary when one group of people have power over others in the allocation of resources to meet their needs. For this reason my new model will emphasise 'lifestyles' rather than 'needs' or 'services'. This is a more dynamic approach which avoids dividing us up into diagnostic categories (like the World Health Organisation classificatory system of disablement) each of which then becomes possible to allocate to a different professional worker. I have called this an **interactive diversity in lifestyles model** and it covers *both* the models of disability and models of intervention that are actually used by professionals in the Welfare and Chartered States.



With this in mind if we look at the conceivable lifestyles of disabled people then we are faced with an infinite variety of situations which might be entered and many diverse activities that could be carried out. Disability, quite simply, is concerned with the barriers that may prevent this. It is not about *who* we are or what might be *wrong* with us, as professionals and politicians with abilities would have us believe. A dynamic approach means we look at the total social

situation in which everyone interacts and the diverse illnesses we all might face in these different circumstances. This is what might be called a **diverse interactive model** of disability – i.e. people with abilities can also become disabled by barriers!

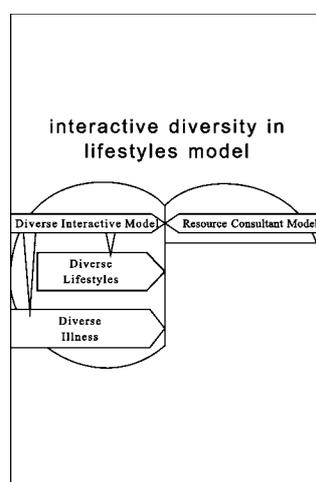


For *all* human beings a critical advantage of living in societies is that this enables mutual assistance in the successful exploration of the variable physical and social world. For disabled people this also means the removal of physical barriers created when the environment is designed for able-bodied lifestyles and is simultaneously packaged with restrictive attitudes, expectations, culture, traditions, laws, regulations and so on. Whereas people with abilities are expected to obtain assistance through the provision of *normal* services (such as 'public' transport) until these are barrier-free people will be disabled and forced to enter the social and physical world only with the assistance of additional specific resources (such as special transport). For *everyone* to regain their human dignity and right to social choice, denied in the Welfare and

Chartered States, we require access to workers who can be consulted about appropriate resources needed in overcoming the disabling barriers that we face. These resources may be provided, I believe, in a **resource consultancy model** for the provision of services.

The long-term objective is to look at ‘lifestyles’ in a comprehensive way so that social support for disabled people is not controlled by professionals working according to guidelines cemented in boundaries between inappropriate models of disability and intervention. Holistic, interdisciplinary or multidisciplinary approaches within the Welfare and Chartered States attempt to break through such boundaries but cannot succeed because they are promoted by professions which are *already* confined behind walls built on set models of intervention. The long-term objective cannot be anticipated by implementing holistic approaches artificially.

A model is needed which opens doors between boundaries while recognising that there cannot be a quick or easy answer. With this in mind the goal must be a close connection between what it means to be a disabled person and the support needed by each individual to achieve their own aspirations. People with abilities, as already mentioned, naturally construct services to provide their mutual assistance along these lines. We need to bring the issues of identity and associated service provision out of the *specialist* culture of ‘care’ into such a *mainstream*



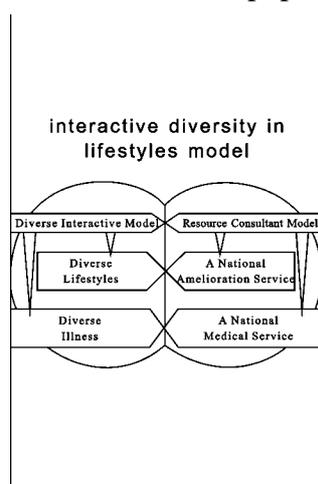
culture of ‘support’. A model, then, which could replace the Welfare State’s approach to ‘care’ for people who are diagnosed as possessing personal deficits or replace the Chartered State’s approach to legalise ‘rights’ for people who are identified as facing ‘unfair’ discrimination must also apply to *all* population groups. In my view a **diverse lifestyles** interpretation of human social functioning would include disabled people alongside all their peers. In this approach disabled people are only one of many equal but socially diverse groups and the need for a specific model of disability becomes less important.

There is little disagreement amongst informed disabled people that giving doctors the foremost decision-making powers over all health issues, through the NHS, has effectively granted them supremacy over the classification of disabled people and the identification of

the services we are supposed to need. The result has been a damaging bond between disability and illness so that there is widespread resistance amongst professionals with abilities to the separation of ‘medical’ issues from problems in social functioning (civil rights). The NHS, of course, has profoundly contributed to such a confusion in many areas – for example childbirth. Disabled people, therefore, have an interest in promoting a clear medical contribution to our well-being while at the same time limiting medical control over our lifestyles. Such demands have commonly been interpreted by the medical profession and professions subservient to medicine (PSMs, often referred to as Professions Allied to Medicine – PAMs) as being ‘anti-medicine’. This is untrue. The intention is to promote clearer identification of medical issues and its appropriate field of intervention from the basic *health* concerns which require action in other diverse ways. Building a model which covers ‘diverse interactive’ human behaviour, therefore, must also include **diverse illnesses** alongside the ‘diverse lifestyles’ with its broader social concerns.

Strictly speaking, this ‘diverse interactive’ model, and all of its sub-divisions, does not exclusively concern ‘disability’. The focus is on the mosaic of human behaviour. This includes disabled people’s varied lifestyles. To be of use the model should throw new light on the meaning of ‘being human’ *before* it really becomes a tool to begin gaining radical insight into the nature of ‘disability’!

When we start looking at possible ways of organising ‘interactive’ services for a population with diverse lifestyles, rather than providing special services for ‘the vulnerable’, those who have ‘problems’ or those who ‘deviate’ from people with abilities, a creative pattern for the future might be better laid on more natural foundations – that is, the way non-disabled people spontaneously fashion publicly accessible support services to meet their own multiple everyday requirements. For example, a restaurant is a ‘meals-on-wheels’ equivalent for people with abilities. There is nothing *special* about ‘caring’ for *their* meals. It is a natural part of the diverse population’s variable service requirements for their daily needs. My ideal for future services for disabled people who are *not* ill, then, ought to be developed and provided along the same principles. This means integrating the services so that they are unified and can assist the entire national population achieve the goals to which each individual aspires. This is not



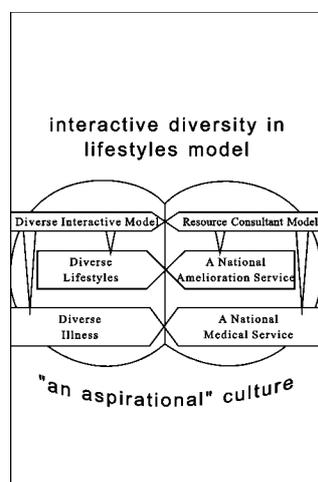
only a holistic approach to enrich everyone’s quality of life but is based on universal human characteristics to ameliorate life’s chores whenever possible. I call this approach **a national amelioration service**.

At the heart of such a service is the principle of *integrating* the way we organise society so as to assist each other achieve our personal aspirations. Disabled people created this type of service when they set up Centres for Integrated Living. This undertaking attempted to integrate our assistance into the social services structure of the Welfare State. This, of course, could not succeed because ‘Welfare State’ services were constructed within cast-iron boundaries between statutory provision for disabled people and people with abilities. The ‘Chartered State’ maintains these boundaries while

employing the legal profession to manage and supervise policing the boundaries and so, it too, is not conducive to the establishment of *integrated* living services. In general the emphasis in Centres for Integrated Living is to provide a location for services which integrate disabled people’s aspirations into the normal fabric of society. This contrasts with the Centres for Independent Living, mentioned in the Chartered State’s service structure, which aim at supporting the independence of disabled people within the market system. In the resource consultancy model for services Centres for Integrated Living could become a key provider of amelioration services for *everyone*, not just disabled people.

Disabled people, like *everyone* of course, can get ill – not because we are disabled people but because we are human beings (although our impairments may make us more susceptible to infections and debilitating problems than non-disabled people) – and like everyone we need good medical attention at times. If diverse lifestyles are supported in a national economy by an amelioration service this is bound to cover interventions which promote the development of a healthy environment (for example, good housing, water supply, efficient sewage, ‘organic’ food, etcetera). This approach also includes accessible facilities to enable healthy living (for example, local gyms with equipment for all, changing the rules of sports and sporting facilities so that everyone can participate, an accessible countryside, etcetera). In this way nearly all ‘health’ concerns, activities and facilities would be located outside medical control and there could be no health *service*. This means most physiotherapy and all occupational therapy could be incorporated in new professions located in the community and beyond medical corruption. Medicine, then, could focus on the cure and alleviation of illness in **a national medical service**. Since disabled people’s specific service requirements would be met by the national amelioration service (in Centres for Integrated Living) the medical model of disability would no longer make any sense.

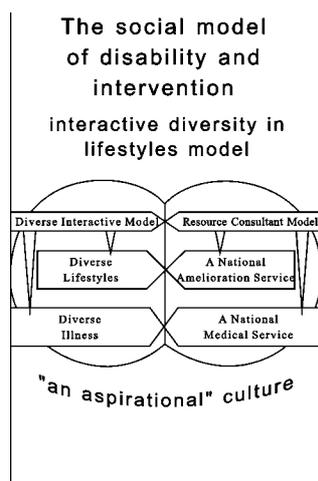
All the components of the model I would use in the construction of a non-disabling society are now in my kit box. However such a world can only become a *reality* when there is a fundamental shift in people's greedy self-advancement and worship of the body-beautiful



instilled by the Welfare and Chartered States. What is needed is the glue to hold the pieces together. For this I would use **an aspirational culture**. In my model for the future 'who we are' and 'what we want to do' would be valued. The goals we set for ourselves would be respected and support from a multiplicity of services would naturally be available to help everyone realise their aspirations. People who have impairments would not be disabled by the values and structure of a society designed for able-bodied living. It is disability arts that would have a special role in revitalising these positive qualities of humanity, presenting equalitarian values to a wider public arena and assisting everyone regain their sense of intrinsic worth. The emergence of a national aspirational culture, in my modelling kit, is very much dependent on the successful maturation of disability arts! If, however, disability arts goes no

further than emphasise the experiences of being disabled (as the advocates of the *rectified* social model of disability now attach importance to) it will lack the creativity to fulfil its destiny in helping move society beyond the illusions of the Chartered State. An aspirational culture, then, is a vital item in emancipation and the reason why it was packed into the modelling kit many years ago.

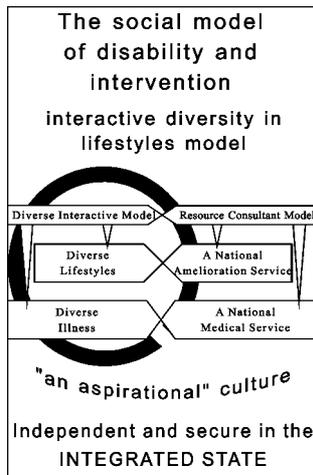
The model pieces are far from clearly moulded, pre-packaged for anyone to purchase, open, begin assembling and subject to emancipatory testing. Some pieces are still in their wrapping, waiting to be opened and made ready for gluing together with others. Some pieces are still



unformed and need much attention before they are of use. There may be some pieces missing, which we will only notice when we try to fit them together. Some pieces have fallen into our box from other kits and will never belong in our model. Despite the imperfections in this kit, however, I believe we can now start to see the real dynamic shape of **the social model of disability and intervention**. Clearly, models provide no simple prescription for eliminating oppression. Nor do they explain why we come to be trapped in particular disabling situations. Used imaginatively, however, they can give us insight into old problems and raise the prospect of finding solutions which otherwise escape us. The social model of disability has been much admired and abused. Few, however, have actually opened the kit, unpacked the pieces and really begun trying to fit together this wonderful new tool. It is only

when this interpretation of disability is repossessed by ordinary people, when they become the owners, when it is explored, manipulated, taken apart and reassembled that its full value will really be appreciated and its value become ingrained into our national personality. The social interpretation can then assist us to set goals for the future rather than merely act as a mirror of the present.

I hope, with the modelling kit open, many of the pieces in front of us and the sketch plan providing at least some guidance, that there are enough pieces to construct a social model of disability that brings new insight into the kind of non-disabling society we might all want – a society in which people who have impairments, alongside other population groups, can really celebrate their humanity. In this new society *all* people would have access to national medical and amelioration services which enable them to be **independent and secure in the integrated state**. This contrasts with the dependency creating values idolised in the Welfare State and the competitive independence worshiped in the Chartered State. The model also promotes a leading role for disabled people in the creation of a more humane society and completely rejects any notion that, *unassisted*, people with abilities (with their self-reverence for the body-beautiful) are capable of leading humankind out of the mess into which they have led it. Far from being permanently dependent upon people with abilities to be included into *their* disabling society, this model reverses roles and suggests that it is disabled people who can make an independent contribution to the emancipation of humanity!



## 6 FINISHING TOUCHES

*'Let me pass, I have to follow them, I am their leader.'*

(Alexandre Auguste Ledru-Rollin, trying to get through a crowd during the French Revolution of 1848).

In whichever state shop they are marketed models sold to the public are often only a source of fame, privileges, honours and even emancipation for the elite. The disabled grassroots purchaser, on the other hand, may have to pay the price of continuing dependency on the model vendors. A production line run by disabled educationalists and researchers producing well-packaged models in a 'modernised' learning materials university factory might in reality only be selling fashionable entertainment toys underneath the academic wrapping. Once opened the 'consumer' may find few pieces to assemble, no finishing touches to add and little to admire or discover before familiarity breeds disillusion and indifference. Is the privileged disabled social model-maker, we have to ask, becoming no better than the much criticised parasitic professional with abilities?

If models are constructed to help us gain insight into situations which otherwise are difficult to *begin* explaining a rectified social model of disability which actually services the needs of the Chartered State may have an immediate appeal but a short use life. This in turn will drive the academic factory into producing and marketing an unending range of 'modernised' models. The formation of a guild for advanced model makers may be the only real material gain achieved by the learned promoters of such social models of disability. No wonder, then, that there is a growing disability elite, consorting with influential people with abilities, and competing for student 'consumers' in the new supermarket for a swish new-fangled social model of disability. What is really needed for our emancipation, however, is a tool which will enable disabled people at the grassroots level gain insight into their major and decisive role in the creation of a non-disabling society rather than a model which merely clones the current social fashion for their entertainment. When opening a modelling kit we should ask, then, what revelation might it provide in constructing the future or, at the very least, in providing insight into the past?

For example:

The 1944 Disabled Persons (Employment) Act introduced the 'quota system' where organisations employing more than twenty people were obliged by law to ensure that three per cent of the workforce were registered as 'being disabled'. This should have resulted in increased employment for disabled people. It never did, and the legislation was not enforced. Opening my modelling kit I would locate this legislation within the administrative model for service provision in the Welfare State. Looked at from the angle set by this model the 'quota system' now appears fundamentally inconsistent. On the one hand the quota should encourage secure financial *independence* through employment while on the other hand the Welfare State assumes disabled people are permanently *dependent* on others for their security – a contradictory and unreliable formula for intervention. With hindsight we should have expected that a scheme to make the 'socially dead' independent through employment could not really be viewed by employers or the Welfare State regulation enforcers seriously and would, therefore at best, only be implemented in a half-hearted way. As we move into the Chartered State the quota scheme becomes redundant because it can be replaced by an emphasis on equal opportunities law. A similar predication of failure could have been expected for the Welfare State's approach to a National Health Service – *health*, of course, embraces all aspects of people's lifestyles and cannot be *serviced*!

Looking forward, for another example, we could focus on the ‘national amelioration service’ piece of the kit’s social model of disability in the Integrated State:

This service, I have suggested, could be provided by Centres for Integrated Living (CILs). An amelioration service would work *with* rather than *for* the community as in the Welfare State, or rely on aggrieved individuals obtaining assistance from an *extant* (legal) profession for their equal opportunity rights in the Chartered State. In the Integrated State assistance would come from *new* professions created by, and allied to, the community (PACs), employed in CILs and managed by representatives from all sections of the community. Working with disabled people (or other population groups) PACs could:

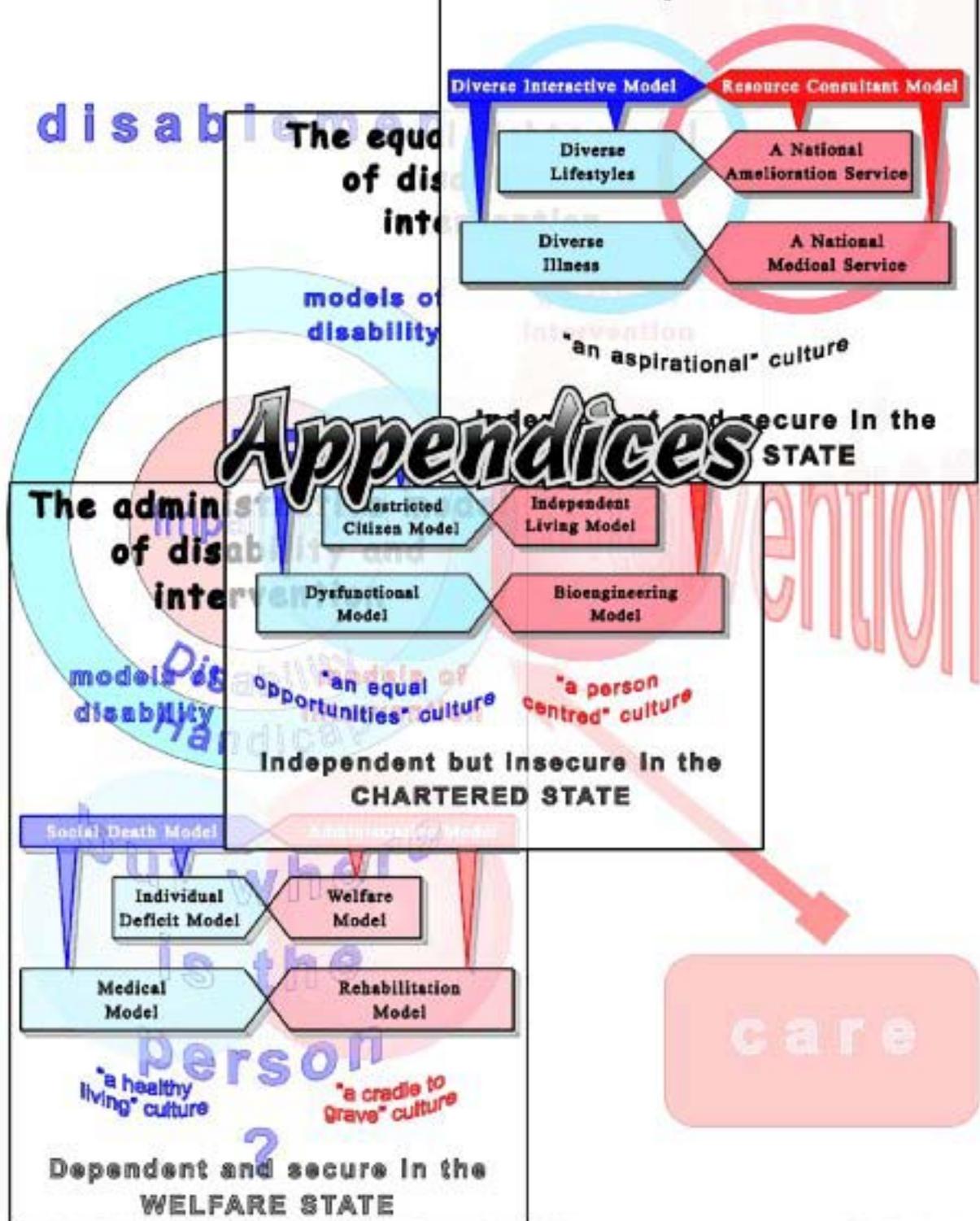
- help individuals identify important personal short and long-term lifestyle aspirations,
- assist people obtain the necessary resources to realise self-defined objectives,
- collaborate with other social agencies and services to remove social barriers impeding diverse personal goals,
- obtain the necessary resources to enable individuals realise their aspirations (in a non-disabling society),
- assist individuals cultivate skills to achieve specific targets signposted by their lifestyle preferences, and
- above all, work with individuals commensurate with their abilities and subservient to their management choices.

What, no *needs assessment*? Yes... Unwrapping the kit and fitting the parts together reveals that an entirely new piece is required to complete the social model of disability – a new profession with different objectives, lines of management and ways of working with the community. The model does then, I hope as models should, provide new insight into our predicament. Clearly to translate the model into a working reality we need to cultivate grassroots consensus in a long-term campaign for our own profession alongside an escalating boycott of collaboration in the maintenance of Professions Subservient to Medicine (PSMs). Here now is a creative role for the disability cultural movement. Nothing short of a revolution in grassroots consciousness is required because it is only from this direction that academics in ‘disability studies’ can be brought under control to *serve* disabled people by creating qualifying courses for the new profession. Left alone they become an elite capable only of interpreting the world in various ways; the point is to change it.

Our organisations *of* disabled people are *vehicles* for change  
Our unionised profession allied to the community is a vital *engine* for social change

# The classic model of disability and intervention

## The social model of disability and intervention



# Appendices

# The classic model of disability and intervention

**disablement**

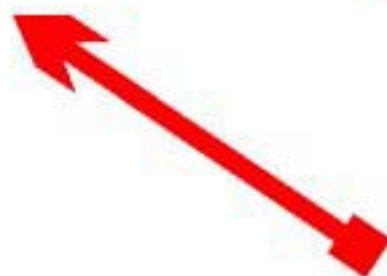


**but where  
is the  
person  
?**

**cure**



**intervention**

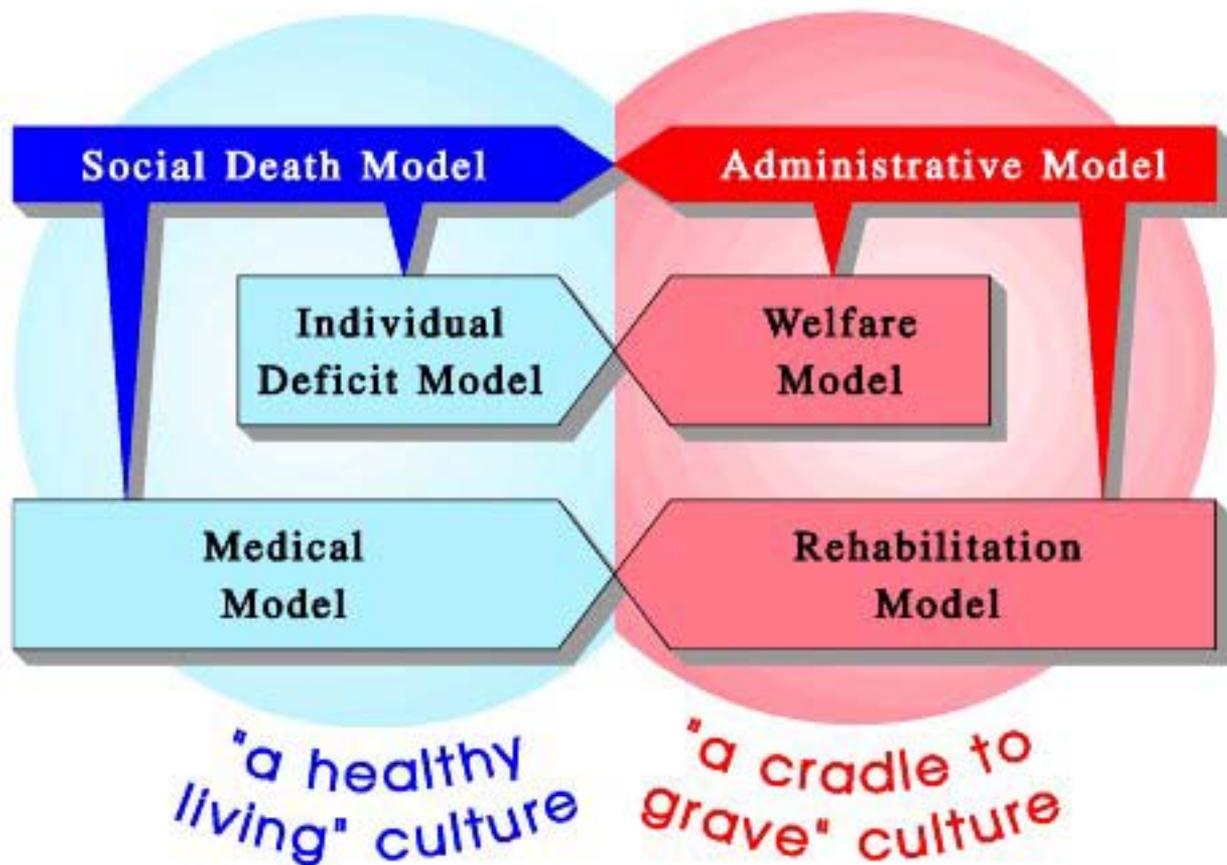


**care**

# The administrative model of disability and intervention

**models of  
disability**

**models of  
intervention**

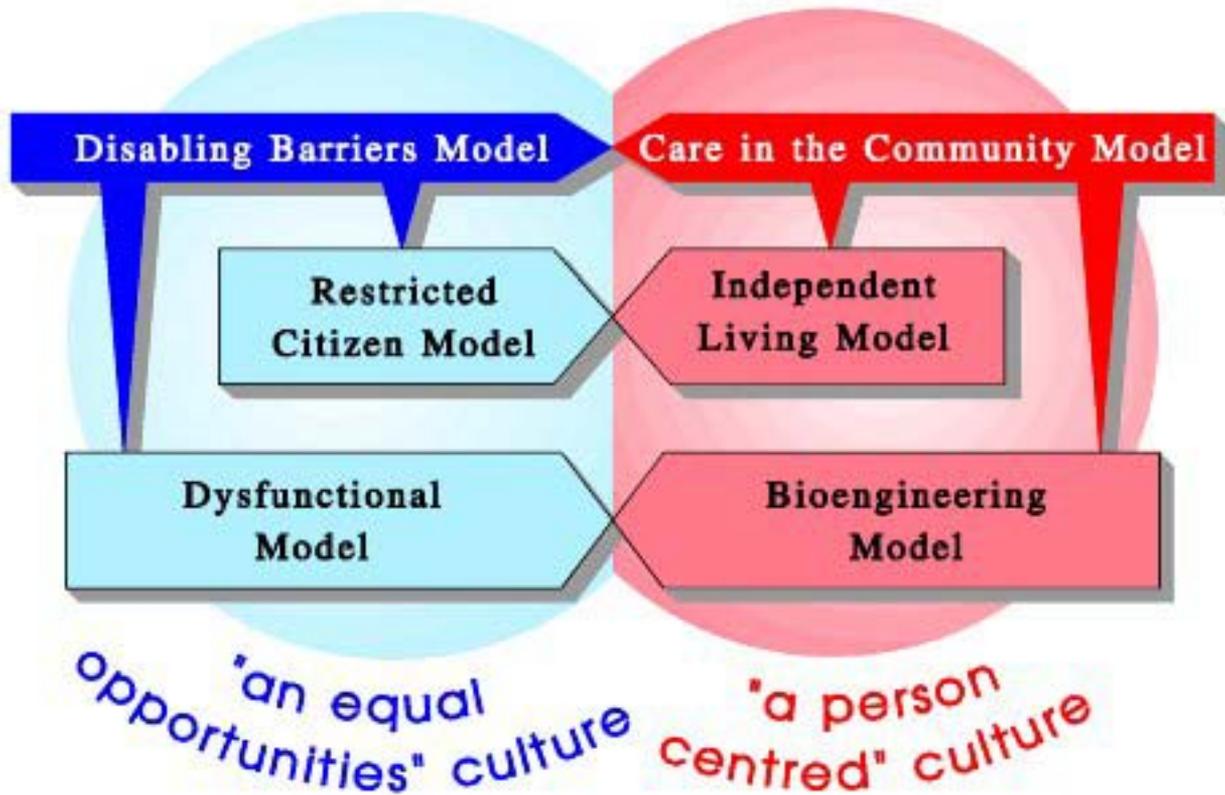


**Dependent and secure in the  
WELFARE STATE**

# The equal rights model of disability and intervention

**models of  
disability**

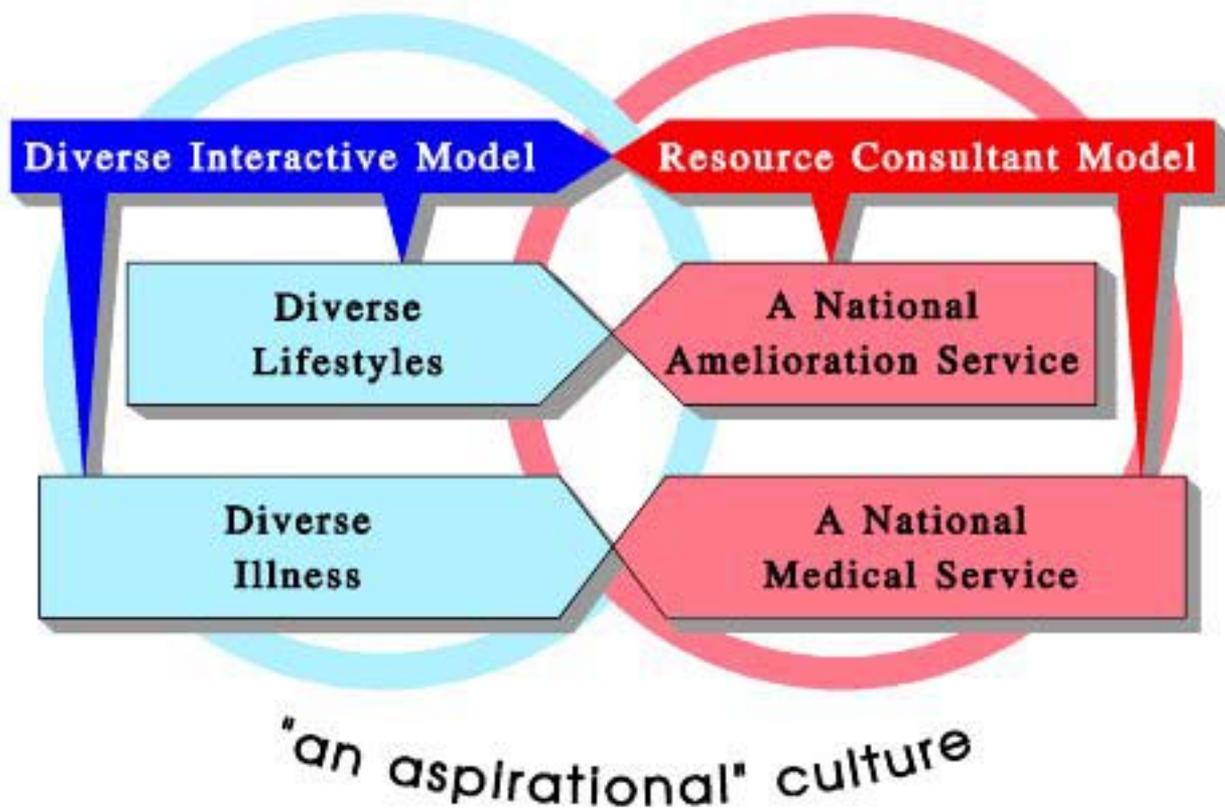
**models of  
intervention**



**Independent but insecure in the  
CHARTERED STATE**

# The social model of disability and intervention

## interactive diversity in lifestyles model



**Independent and secure in the  
INTEGRATED STATE**