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Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

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By Luke Hewitt

Contents

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Acknowledgements

By Luke Hewitt

Abstract

In deriving a new definition of disability, it was first necessary to examine disability from an independent perspective which, while it took into account previous medical and social definitions, did not start from the basis of either. Thus, disability was considered first as a generally purposive term, and then examined in its application to humans. In this application, though social factors and the thinking of the medical profession were addressed, it was concluded that disability was an intrinsic state of the self, which could be distinguished as independent from social interactions. This state was characterized by its effect upon the disabled person's ability to fulfil desires, both in terms of its direct preclusion of some desires, and its ability to make other desires require extra effort. The question of normality was then addressed, and it was concluded that disability could be defined organically as any involuntary state of a person's biological or psychological self that resulted in detrimental effects upon desire fulfilment as compared to other individuals in a similar environment.

The question of individuals with cognitive impairments and others unconscious of their disabled state was then addressed, and, though there has been comparatively little written about such individuals, their lives and ability to fulfil desires were examined in detail. It was concluded that people who are cognitively impaired should be considered as temporally impaired, and thus possessing the status of children when the definition was used to consider the fulfilment of their desires.

The desire based definition was then used to address several issues common to the practical experience of disability including accessibility: the use of environmental adaptations and non-human aids for the fulfilment of desires, human or animal assistance, and the problems inherent in the power relations between disabled and non-disabled individuals. The question of when desires could legitimately be modified to make their fulfilment possible under the conditions of disability was then also considered, which led finally into a discussion of social attitudes to disabled people;since, though according to the desire based definition disability was not identical with such attitudes, it could be heavily affected by them.

Some recommendations for the consideration and conduct of disabled and non-disabled individuals were suggested. These began with a discussion of a disabled individual's need to develop competency in dealing with their disability, and a corresponding problem of society's insistence upon perceiving disabled individuals as intrinsically different beings. It was suggested that the possible establishment of independent adjudication, in cases where the assessment of a disabled individual's capabilities was subject to bias, would help to alleviate this damaging social perception.

Finally, it was affirmed that disability, though a negative state, was not an uncommon one; it constituted a basic relationship between a person's involuntary physical or psychological makeup, their desires and the world, and one which most people would at some time experience. Thus it was recommended that the concept of disability needs to be

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

considered as no longer a specialist one, but one that should be part of our usual, everyday relations to our environment, our desires and their fulfilment.

By Luke Hewitt

Chapter 1: Defining disability with respect to quality of life

Introduction

Before the 1970's, what constituted disability was held to be a comparatively simple matter. If a person had an illness or injury such that they lost the ability to see, hear, move freely, etc., they were disabled. What form the disability took, and what individual words were used to describe it were simply a matter of semantic difference and medical convenience, describing symptoms of a disease or injury, the way that infections of the liver, kidneys or other bodily organs, though requiring slightly different treatments, were all essentially similar in that they were all categorized as forms of infection. Indeed, as Swain argues, medical definitions of this time were rarely concerned with the effects of symptoms, merely that the symptoms existed.[1] Thus, you could measure a person's "remaining vision" but such a measurement was held to be simply a statistic revealing how damaged a person's visual organs were. It made as little sense to ask why the nature of this damage, i.e. "being blind", was a bad thing, as it would be to ask why the symptom of physical pain produced by an organ infection was a bad thing.

When such "defects" could not themselves be corrected medically, the recommended (and often followed) course of action in dealing with people so injured was held to be medical care. A person with such a condition could not live "normally" in society, so needed to exist in an environment where their condition could be "cared for", either at home or in state-run institutions. "Disability" therefore differed comparatively little from any other long lasting, incurable medical condition such as cancer, and required a similar answer.

Then, in the 1970's and 80's, various academics, particularly sociologists, began to take exception to this view.[2] They argued that just as prejudices, such as racism or sexism, were based upon a "normal" ideal that being of a certain race or gender was automatically better, more normal and more desirable, the medical idea that being "disabled" equated automatically to an obviously bad medical symptom was a form of "ableism". The social model, as this became known, is founded upon the idea that the problems experienced by a person who is diagnosed as disabled, are in fact simply imposed by the prejudicial beliefs and social practices of the able bodied majority. People with hearing impairments for instance, as Silvers mentions, only experience difficulties in communicating because the majority of people communicate aurally, rather than visually.[3]

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[1] John Swain, Sally French and Colin Cameron, "Chapter 1: What's in a Name?" *Controversial Issues in a Disabling Society*, (Buckingham: Open University Press, 2003).

[2] Ibid, "Introduction".

Also: John Harris "Is There a Coherent Social Conception of Disability?" *Journal of Medical Ethics,* vol. 26, (2000), pp 95-100.

[3] Anita Silvers, "Judgement and Justice: Evaluating Health Care for Chronically Ill and Disabled Patients", *The Blackwell Guide to Medical Ethics,* ed. Rosamond Rhodes, Leslie P. Francis and Anita Silvers, (Maldan, MA: Blackwell, 2007), pp 354-373.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

This model's chief focus, as Swain notes, is therefore how the non-disabled population interact with groups of people who are characterized as disabled, on a political, individual, and cultural level. It is therefore unsurprising that many of the advocates and writers in the social model are disabled themselves, and often seek to articulate their experience of "participating in" the cultural identity of a disabled group, and clarify to the non-disabled majority how the experience of those possessing that identity can be improved.

Having lived with visual disability myself, I do have sympathy for this project. On a level of daily experience, it is certainly true that people make assumptions and judgements about me, my capabilities, preferences or desires because it is perceived that I am "blind" with no other data: this is a prejudice in the most literal sense, i.e. a pre-judgement, and it is certainly true that the nature of this pre-judgement has caused me to directly experience exclusion, ignorance, cruelty and other forms of harm.

Equally, however, it does not seem I can automatically lay all the experiences I have related to blindness solely at the door of my interactions with society, nor is it frequently possible, when comparing my experience to those of other blind people, to say that I am "participating in" any kind of group identity or shared culture; indeed, often my experiences are as naturally different from those of other blind people as they would be from those of any other unique individual.

For instance, if, while writing this chapter, I desired a glass of water, I need to first locate the glass using tactile scanning and (if close enough) my remaining vision, then walk to the tap, maintaining the memory of my current environment and any possible obstacles I might encounter in the way, then fill the glass from the tap, with my finger over the edge to prevent the water overflowing. A person with normal vision could accomplish this task far more easily than I can, not requiring either use of memory or concentration with their direct visual perception of the world, however it certainly doesn't seem correct that this disparity in accomplishment is the fault of society, or a part of a larger group identity, since the only person currently in control of my environment is myself, the only person with the desire for a glass of water is myself, and the only person involved in the difficulties fulfilling that desire is myself. Indeed, other blind people may follow significantly different practices in attaining this desire, for instance relying upon another person's assistance, or using electronic liquid indicating devices or tactile markers, and may be more or less successful in fulfilling all the components of this desire than I am, purely as a matter of their individual circumstances, choice and environment.

Just as the social model criticizes the medical model for looking at all disability simply through the lens of symptom, illness and cure, I find myself thinking that perhaps the social model is guilty of a similar lack of perspective in attempting to characterize and encompass all disability relations only by virtue of interactions between specific social groups or indeed, with society as a whole.[4,5] There is then the related problem of what

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[4] A similar concern is indeed raised by Chappell, who notes that the majority of commentators in the social model are overly occupied with the "body image" of society and the validity, or otherwise, of the experiences of those wit physical disabilities, whereas for those with learning disabilities, there is neither a "body image" nor an opportunity to articulate their own life experience. I will return to Chappell's thoughts on learning disability in the second chapter.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

precisely links my experiences to those of a deaf person (who would find pouring a glass of water as easy as a fully sighted person), or indeed someone with learning disabilities, mental illness, or paraplegia, even though we all fall under the broad umbrella categorisation of disability.

Much of the literature on this topic does not address these questions directly but tacitly assumes that some form of the social model is correct, and spends significant amounts of time arguing on its precise nature, or on the nature of those medical classifications of disability which led to the formulation of the model in the first place. This is unsurprising since a good amount of the literature is written from the point of view of sociologists or political activists, who naturally have a vested interest in the interaction between groups of people, i.e. disabled and non-disabled, us and them, or "normal" versus "abnormal".

These views may be of help sociologically or politically, but it is my belief that just as a purely medical view of disability, as merely the symptoms of a disease or injury, fails to capture the full essence of a disabled person's experience due to its uniquely medical context, the social model fails because of its almost exclusive focus upon social interactions. For this reason I believe it is necessary to step back to first and original principles. Rather than starting with any existing definitions of disability, or even the theoretical lens of medical or legal terminology by which disability should be characterized, I believe it would be most helpful to begin from as wide an angle as possible, and, as Socrates might have done, start by asking the question of what the word "disability" actually means. From such semantic and theoretical concerns, I will attempt to create a workable definition of disability from the ground up. After the basic semantic and ethical question is considered, I can then move on to address points related to individual experience, social interactions and the nature of the body, leading to a consideration of the previous models, but from a viewpoint not committed to either.

I hope that such a definition will be able to take into account the medical state of a person's body and its functions, and also the better aspects of the social model, without being forced to put all the definitional eggs into one sociological basket. Thus I will attempt to create a flexible enough definition that will provide knowledge of how to classify a given condition as a disability and identify in what ways such a condition influences the life of someone experiencing it. In clarifying these aspects, I believe such a definition can then be used to more accurately discuss important concepts like the status of those with learning difficulties, accessibility, the nature of human assistants and their relationship to a disabled person, and what part social prejudice does in fact play in influencing the lives of disabled people even when we assume that the disability itself is not simply identical with such prejudices. Therefore, I will first attempt to reach a concrete and useable definition of disability, beginning with the uses of the word "disability" and moving on to the basic quality of a person's life, and how disability may be defined with respect to its effects upon that quality of life.

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[5] Anne Louise Chappell, "Still Out in the Cold: People with Learning Difficulties and the Social Model of Disability", *The Disability Reader: Social Science Perspectives*, ed. Tom Shakespeare (London: Continuum, 1998), pp 211-221.

By Luke Hewitt

In Section A I will discuss disability as a purposive term, and how this relates to the common medical understanding of disability as an abnormality which affects our well-being. I will contrast the bad effects of disability on well-being with the irreducibly unpleasant notion of medical conditions that cause physical pain, and in what ways the notion of disability seems to differ from this basic standpoint of harm.

In Section B I will attempt to establish the precise location and scope of the harm done to well-being by a disabling condition, whether it is (as contended by theorists in the social model) purely a matter of a judgement made of certain individuals by society, rather than being integral to a disabled individual's physical or psychological self, as is commonly thought in the medical model. I will attempt to establish a firm grounding for the idea of disability, and define what may, or may not, count as disabling. I will then attempt to square this with social expectations, and the senses in which disability is involuntary.

In Section C I will discuss the relationship between disability and the desires and pleasures of an individual, and introduce the notion of capacities for well-being.

In Section D I will consider the relationship between disability, effort and time, and how the effects of disability may alter on a daily basis, and how in turn this affects a person's general well-being.

In Section E I will consider the notion of "normal" as a contrast to the notion of "disabled" and attempt thus to re-introduce a standard of normality which is compatible with the capacities for well-being approach I am following here.

Finally, in Section F I will use the tools I develop throughout the first five sections to formulate a definition of disability that may be of use in practical and ethical debate.

By Luke Hewitt

Section A: Purpose and the common medical understanding of disability

In its conventional linguistic sense, the term "disabled" seems to apply in just as straightforward a fashion to a group of humans as it would to any other objects, namely the frustration of some part of their "normal" functioning or purpose. In a computer program for example, a certain part of the program may be disabled which will interfere with the "normal" task the program is being asked to perform, and the program would generate an error message as a reasonable explanation as to why the task could not be performed, for example an E-mail client might say, "Could not download messages, internet connection disabled". We accept such explanations mean that some part of the usual, causal chain of events that leads from the user of the program giving an instruction, to that instruction being carried out, has failed in some way because one or more processes necessary to carrying out that instruction could not be followed through, and thus the entire function is frustrated, and the program is not fulfilling its purpose. In all other respects, the E-mail client might work quite correctly, be able to display text and pictures, format E-mails, etc., however with the connection to the internet "disabled" the basic purpose of the program, to send and receive E-mail messages, is no longer fulfilled.

This relation to function or purpose is made even clearer when we consider, in contrast to disability, the word "ability": if a thing, person or object is "able" i.e. has the ability to fulfil a specific function, we can assume that, other than by the intervention of external agencies, that function will be fulfilled, for example if it is claimed that a train is able (has the ability) to arrive at the station at a certain time, we would expect it to do so. In cases where an object does not have the ability to fulfil its purpose, we usually will require some explanation of either an external or internal cause as to why said purpose was not achieved. So in the case of the train, it might not have been able to reach the station at five o'clock because the tracks were damaged (an external cause), or because its electric generator was broken (an internal cause).

The relationship between purpose and disability or ability also holds in statements about human intentions, such as, "I am able to meet the train at five," and once again, if I fail to achieve this purpose, it would be reasonable to ask for some sort of explanation as to what occurred in the causal chain of events between my having the intention to meet the train, and my failure to arrive at the station at five o'clock.

Fundamentally then, disability in this broad, conceptual sense includes the idea of enacting a purpose, fulfilling a function, or working towards a goal. This seems all very well when applied to manufactured or specifically designed objects such as computer programs, trains, or even human intentions to act. Such a created object is by virtue of it being the intentional work of its creator, designed to fulfil some kind of purpose, for example downloading and displaying E-mails in the case of an E-mail client, or travelling between stations in the case of a train.

It is therefore very easy to determine when such a designed and created object, is, or is not, fulfilling its purpose, by examining the initial intentions of the designer, and comparing the performance of the object, and the state of affairs caused by it, to the results its designer was intending, i.e. the purpose for which it was designed. Likewise, a human intention is said to be fulfilled only to the degree that the outcome of events matches the

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

original intent.[6,7] If some aspect of the created object is "disabled" it's entirely possible that its purpose will be only partially achieved, or not achieved at all, and we accept the disability of whatever aspect of the object is involved as a sufficient reason for this lack in achieving purpose.[8]

When the term Disability is applied to humans however, it has a slightly different and much more wide ranging meaning. It seems that in its conventional use, saying a person is "disabled" is saying significantly more than simply identifying one aspect or feature of that person which causes them to be unable to fulfil some sort of purpose. Indeed, it has a far more judgemental overtone than the basic assessment as to whether a purpose is achieved or not.[9] For instance, saying, "John could not read a newspaper because he is disabled," has very different resonances to the apparently functionally equivalent statement: "John was unable to read a newspaper", since assessing John as "disabled" implies far more about John's life, circumstances and abilities than simply whether he was or was not able to read the morning news. It is for this reason that Jones observes that when a person is called "disabled" it disproportionately alters the amount of praise or blame that person's actions receive from others.

Brisenden also notes the common attitude that frequently mundane actions and facts of the lives of disabled people, such as living alone or carrying out housework are taken as great achievements, while actual achievements are viewed as being carried out "in spite of"a person's disability. Conversely, as Brisenden continues, in other cases a person's actions or motives are judged more stringently because they are "disabled". Thus the evaluation of a person's actions and their consequences subtly changes far more than a simple statement of lack of ability would dictate, whether or not said actions were in fact affected by the disability at all (a matter I will return to in Chapter 4).[10]

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[6] There is of course, a considerable debate among ethicists, outlined by Sumner, Griffin and others, specifically related to the desire theory of happiness, as to when, precisely, we can count a particular desire, or even a mere intention, as being fulfilled. For the present though, it is sufficient for our purposes to note that the term "able" provides a bridge between intention and result, a bridge which if cast down completely frustrates the whole structure of intentional desire fulfilment. The further implications of this debate, and how fulfilling our desires relates to the conventional understanding of disability will be discussed in Section C.

[7] L W. Sumner, "The Subjectivity of Welfare", *Ethics*, vol. 105, no. 4, (1995) pp 764-790.

Also: J. Griffin, "Chapter 2", *Well-being*, (Clarendon Press, 1986).

[8] Of course the terms "disability" and not being able (inability), have slightly different uses, since the term disability is intrinsic to the object or person, whereas inability may equally be extrinsic, as with the example of the train and the damaged tracks, and even in cases where "inability" is used as an intrinsic property of an object, its use differs significantly from that of the word "disability". I will discuss the question of these differences further in Section B when I deal with the involuntary nature of disability.

[9] R.B. Jones, "Equality and Disability Symposium: Impairment, Disability and Handicap - Old Fashioned Concepts?", *Journal of Medical Ethics,* vol. 27, (2001), pp 377-379.

[10] Simon Brisenden, "Independent Living and the Medical Model of Disability", *The Disability Reader: Social Science Perspectives,* ed. Tom Shakespeare, (London: Continuum, 1998), pp 20-27.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

This disparity in "disability" in its purely definitional sense, and "disability" in terms of its social and judgemental usage, is the reason many theorists, such as Shakespeare and Culver, make a distinction between "disability" covering group identity and social attitude, and impairment, i.e. what a disabled person can or cannot do.[11] Here, however, I am concerned with the definition of disability itself, and will thus only use "impairment" as a purely descriptive term when discussing specific conditions of a person's body or mind which are conventionally thought of as disabilities, such as physical, cognitive, visual or auditory impairments.

So, this inequity in usage means any analysis of the term "disability" must by its nature be as much experiential as linguistic, since, in its application to humans, "disability" has far more categorical power over perceptions, desires and judgements than in the way in which it is applied to any created objects. Equally however, it does not seem adequate to say, (as theorists in the social model often do), that "disability" in its application to humans is only ever a term of social classification, i.e. that all that is being said when a person is categorized as "disabled" is that they belong to a certain predefined social group. As noted in the introduction to this paper, the experience of living with a disability is far more than just its social ramifications, and the implications and nuances of the word are far broader and more consequential than just its judgemental overtones within society.

This means any attempt to provide a usable definition of disability must be as much phenomenological and rooted in personal perception, as in purely linguistic analysis, in the same way gendered terms such as "female" or "male" could not be adequately analysed from only one context, e.g. just their biological differences divorced from their social or cultural influence, or just their social construction and impact separated from their concrete embodiment within physical bodily experience.

Despite these other concerns however, statements of human disability, as well as whatever other judgemental overtones they may have, are still heavily attached to notions of purposive action and intention. I will return to the judgemental aspects of disability when discussing the assumptions of the social model, but for now it is simply necessary to note the difference in tone of the term "disabled" when it is applied to humans as compared to when it is applied to inanimate objects designed for a specific purpose.

Of course, in the case of humans, defining any overall sense of purpose at all seems a much more difficult task than simply referring back to the intentions of a designer as in the case of a created object. In fact finding an over-arching purpose for human lives is a task which has occupied philosophy for over 2000 years. I will assume here, that the question of overall human purpose is related to living something of a good life, or, as Aristotle put it, eudaimonia, rather than for some other, more external idea of human purpose, such as a Kantian notion of exemplifying the good, or the Christian view of living life according to the will of God, though arguably both of those conceptions may also reduce to recommendations

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[11] Tom Shakespeare, "Chapter 1", *The Disability Reader: Social Science Perspectives,* (London: Continuum, 1998).

Also: Charles M. Culver and Bernard Gert, *Philosophy in Medicine*, (Oxford University Press, 1982).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

for some form of eudaimonia, even if a different form from Aristotle's.

In some traditions, such as that of existentialism, the question of human purpose is entirely left up to each individual human to define for himself/herself, whereas other writers, such as Alasdair MacIntyre, follow Aristotle in recommending that we each perfect certain virtues or excellences in our lives.[12] It seems, however, that "disability" in its basic use automatically impacts upon a notion of a purpose that is more bound up with day to day life, and less of an overarching goal to aspire to, since when a person experiences disability it is the immediate problems of day to day living and relating to others that are most evident, not establishing a general plan or over-arching ethical goal for living. After all, if a person experiences paraplegia and cannot enact basic day to day tasks, such as dressing themselves or shopping, questions of human purpose will, by their nature, need to be second order questions. Similarly, if a person is unable to do something due to their disability and a basic biological restriction (a topic I will return to later) all the speculation of human self authenticity or virtue identification will not change that essential fact, e.g. however much a person with quadriplegia may wish to exemplify the virtue of bravery, they will still have severe trouble getting dressed in the morning, problems which any definition of their disability must address if it is to be of any use in quantifying and clarifying the experiences of those we already call "disabled" as well as letting us discuss disabilities more sensitively in the future. Of course, a person with quadriplegia (or a person with any disability), is quite free to personally pursue any conception of the good, or other life goal they may wish, however such a goal would be independent of their disability, not predetermined because of it, i.e. "Disability" is a state of a person they must deal with, not an intrinsic way of being. The modern tendency of certain agencies and institutions to describe a person with a disability as "challenged" in some way, e.g. describing a blind person as "visually challenged", is perhaps a crude and somewhat facile way of recognizing this fact: that disability is something to be confronted by each individual or group of individuals with a similar disability, rather than a condemnation to reduced circumstances. So "disabled people" are more like soldiers than slaves, i.e. disability presents a set of unpleasant and difficult problems in life which a disabled person must deal with aside from all other parts of life, rather than having their purpose, identity and social status defined only by their capacity to endure a thankless set of tasks for which there is no reward. Therefore, though I will touch upon some more complete and general notions of overall purpose connected with disability later, to begin with I wish to focus on the most common definition of human purpose, and that which our conventional understanding of disability appears to most closely relate to: the notion of well-being or happiness.

I will further assume here, with James Griffin, that "well-being," in part or in whole (at least as far as it relates to disability), involves the satisfaction of some form of rationally attained, compatible, human desires or pursuit of goals, freely and independently determined by each individual.[13] Though Griffin never exclusively addresses the question of disability, his understanding of rationally attained desires, the need to alter desires according to circumstances, and the necessity of individuals to have the freedom to determine their lives'

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[12] Alasdair MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues,* (Chicago: Open Court, 1999).

[13] J. Griffin.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

paths for themselves, are all factors which seem to me central to the phenomenal experience, as well as the conceptual understanding of disability, whether in the harm caused by unsatisfied desires, suffering of pain or other unpleasant states, or the need to rationally understand a person's own circumstances and limitations and perhaps alter their desires accordingly. Griffin's account also gives an emphasis to freedom and need for a person to determine their own desires through both emotional perception and rational judgement, which thus goes further than an account of basic desire satisfaction and also makes it a useful framework upon which to discuss disability and the ways in which it may affect a person's life.

While I will discuss the specific elements of desire satisfaction and their relevance to disability further in this thesis, it is worth noting, even here at the outset, that when I speak of happiness or well-being in connection with a human life, it is Griffin's complex, layered account of happiness related to desire satisfaction that I expressly have in mind.

As Clouser argues, since in the medical model disability involves the lack of, or malfunction of, some capacity or sense which "normal" humans possess as a matter of course, it directly interferes with our quality of life by impacting on either, A, our freedom or, B, our capacities for pleasure.[14] Though accounts in philosophy would give different emphasis to both of these factors with respect to well-being in general, existentialist accounts, for example, placing greater value on freedom, while hedonistic accounts more clearly emphasise pleasure, both would agree that curtailing or impairing either of these factors in a human life would in some way automatically detract from its overall achievement of well-being.

On a basic logical understanding, this seems reasonable. A totally deaf person is denied both the freedom to, and pleasure of, enjoying Mozart, options for both freedom and pleasure which they would have open to them were they not deaf. Though there are undoubtedly people of "normal" hearing who may not have these options, perhaps someone who has never been properly introduced to Mozart, the totally deaf person is at a disadvantage even in this respect, because while the opportunity is always there for a person with "normal" hearing to listen to, and develop an enjoyment of Mozart, the completely deaf person is simply biologically unable to, just as it is biologically impossible for humans to have the ability (as Thomas Nagel famously remarks), to either understand or enjoy the sonar location senses of a bat.[15]

The totally deaf individual, like Nagel with his understanding of a bat's sonar sense, might very well understand the scientific properties of sound. They might know how waves of vibrating air molecules at different frequencies set up sympathetic vibrations in the ear drum which are then transmitted by electro-chemical impulses along the auditory nerve to be decoded in the auditory centres of the brain, but they have no ability, when compared to "normal" humans either to experience, or to enjoy anything related to sound on a

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[14] K. Danner Clouser, Charles M. Culver and Bernard Gert, "Malady: A New Treatment of Disease", *Hastings Centre Report,* vol. 11, no. 3, (1981), pp 29-37.

[15] Thomas Nagel, "What Is It Like to Be a Bat?", *In The Mind's I: Fantasies and Reflections on self and Soul*, ed. D. Hofstadter, (1981), pp 391-414.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

phenomenological level, they could not for example describe a sound as "soft" or "sharp" with any experiential surety.[16, 17] Similar arguments may be made in cases of blindness, lack of senses of smell or taste, deadening of nerves, and paraplegia or quadriplegia with relation to the choice and ability to experience (and presumably enjoy) freedom of movement and the activities associated with it, such as running on two feet.

Clouser therefore categorizes any sort of medical condition or other circumstance which causes these states as a malady, i.e. a source of suffering.[18] By extension therefore, it follows that, if the purpose of life is tied to a notion of well-being or happiness, the "disability" must, to a lesser or greater extent, logically frustrate or diminish that purpose in the lives of disabled individuals as compared to the non-disabled, by decreasing the amount of freedom or pleasure they have access to in their lives, and thus decreasing their overall possible capacities for well-being. Therefore, disabled individuals might be thought of as suffering a similar fate to the victims of a robbery, who are no longer able to gain enjoyment from what was stolen from them, or even (in the case of those born with a disability), have the opportunity to develop such an enjoyment in the first place.

Clouser's understanding of disability is a structured statement of what other writers have named the medical model, since it is the understanding of disability conventionally used and practiced by doctors, nurses and other medical professionals. This model uses a variety of clinical and often statistical tests to determine whether or not an individual is or is not disabled, for example, visual field and distance perception tests are used to decide whether an individual is legally blind: defined as having a distance perception of less than 20 feet, or a central visual field of less than twenty degrees in optimal visibility conditions. The idea that disability in any way causes suffering however, is usually a tacit assumption in medical circles made without express reference to a person's actual experience of the world, and Clouser is one of the few writers who implicitly states why any disabling condition is itself (to use Clouser's phrase) a malady, and thus distinguish a medical condition that causes disability from some other statistically abnormal, but essentially harmless one, such as being born with a heart on the right side of the chest. In the medical model, a person is said to be disabled when they perform abnormally on various medical tests (having less than 20 feet or 20 degrees of vision for example), and this abnormality at the same time directly causes a drop in their quality of life.

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[16] Tom Koch disagrees with this view on the basis that a deaf person can appreciate music via vibrations; however this would seem more to be a different method of appreciating music, similar to a blind person appreciating a statue by touch. It cannot be denied however, that even though a blind person may appreciate the feel of a statue, elements of its perspective, stature, colouring and contextual effect within its setting cannot be freely appreciated, a deaf person is similarly lacking the freedom to appreciate most aspects of music, while a person with normal sight and hearing is still free to appreciate both the tactile qualities of a statue and of music, a fact supported by the popularity of subwoofer amplifiers among those with normal hearing and their placement on the floors of buildings precisely so that vibrations can be transmitted through the floor and felt as the music is heard.

[17] Thomas Koch, "The Ideology of Normalcy: the Ethics of Difference", *Journal of Disability Policy Studies,* vol. 16,(Fall 2005), pp 123-129.

[18] K. Danner Clouser, Charles M. Culver and Bernard Gert.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

A similar definition to this one is presented by Wakefield in his discussion of illness as harmful dysfunction.[19] Wakefield however, rather categorically dismisses disability simply as being that category of illness which impacts the body's function so as to cause a sensory or motor impairment, i.e. when a body's sensory system is affected in such a way as to preclude its "evolved function". He therefore relegates disability to only a comparatively small subset of what medical professionals deal with. I will return to the question of disability and illness later when discussing the question of pain, however it is interesting that Wakefield seems to assume that disability must only relate to some form of dysfunction of the sensory organs, and utterly misses the idea that a person with mental illness or muscle wastage might be disabled, (or indeed the idea that sensory impairments may have other effects upon life than just the reduction of perception). This narrowing of the use of the term "disability" to just cover sensory impairments, clashes significantly with the effects of certain conditions we normally consider to be disabilities, especially those associated with fatigue or extra effort (a topic I will return to later). In general, it often seems that Wakefield is attempting to use the concept of illness to cover ground which our usual linguistic and purposive understanding would suggest should belong to disability, by assigning the "decrease in function" to the term "illness", rather than "disability", thus categorizing someone with a muscle wasting disease as "ill" rather than "disabled".

Unless one accepts the evolutionary explanation of function which Wakefield and certain other writers adhere to, illness is not a purposive term, and is further a term with only tangential bearing upon desire fulfilment, since, saying a person is "ill" only implies that their desires are in some way frustrated in their fulfilment, while saying that a person is "disabled" directly invokes the concept of purpose and thus relates far more immediately to desire fulfilment.

The statement, "John could not read the newspaper because he is ill", does not imply any desire on John's part to read the newspaper, neither is John's "illness" a sufficient reason for his inability to read the paper; perhaps John was simply feeling under the weather and did not wish to burden himself by reading about distressing world events. The substitution of "disability", however, not only automatically implies John's inability to read the newspaper, but also tells us something intrinsic about John's basic capacities, placing him in a social group, as well as giving information about his future prospects of fulfilling his desires.

Therefore, the aspersion that "disability" may be reducible to a small subset of illness seems incorrect, since the term "disability" in our common usage fulfils a very different theoretical and linguistic function and one which could do with its own separate classification: indeed a classification which could assist in the future with definitions of the severity and related effects of illnesses, i.e. defining those illnesses which may cause disabilities, and those effects of illness which may be disabling, as opposed to say, an illness which reduces life span or simply results in an increased risk of developing other ailments.

Though Caroline Whitbeck attempted to create a desire based definition of illness, this largely failed due to the fact that, under our common understanding, a person who cannot fulfil desires may not count as ill, after all, desires may be frustrated for many reasons

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[19] C. Boorse, "Concepts of Health and Disease", *Philosophy of Medicine,* ed. F. Gifford, (Elsevier, 2011) pp 13-64.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and
its Practical Uses in Everyday Life

By Luke Hewitt

external to a person's self quite unrelated to the state of their body or organs.[20]

While it is beyond the scope of what I am trying to do here to provide a concrete definition of illness (see Boorse for many interesting attempts), it is my belief that the effects of any given condition of a person's body or self upon well-being and desire fulfilment is the difference between illness and disability, that "disability" is involved with desire fulfilment, while "illness" covers a far wider range of human experience. While it is certainly true that an illness may cause a person to become disabled, the term "illness" itself should cover a much wider area. For example, it is quite possible to describe The Black Death as "A contagious illness that swept across Europe in the fourteenth century", without any reference to symptoms, let alone anything related to well-being or "disability". Here, therefore, I will restrict myself only to the discussion of "disability", i.e. conditions that have effects upon well-being, and leave the wider definition of illness to others.

Even if we remove illness from the discussion and work with Clouser's simpler version of the medical model, that considers "disability" only as a "malady", i.e. a statistically abnormal condition that causes suffering, we still run into some basic problems with this approach.[21]

The first question we may ask relates to this notion of statistically "normal" individuals. While we are quite aware that there are some abilities, such as possessing a bat's sonar sense, which are (outside the minds of science fiction writers), not in the least accessible to members of the species Homo Sapiens, even in terms of what is available to "normal" humans, it does not seem that the definition of "normal" versus "abnormal" can be so rigidly or clearly adhered to with respect to our pleasures and well-being, particularly when we factor in notions of suffering.

In purely medical terms, "normal" refers to a basic, statistical average, usually established by such procedures as a standard deviation test carried out on a given sample of humans in a population, and then inductively assumed to be true for that entire population. Thus, if 80% of a given sample have characteristic X, it is inductively assumed that 80% of the population will also possess characteristic X, and therefore characteristic X is, for that population, "the norm". In purely scientific terms such a process makes sense, and is no different from claiming, for example that Grey squirrels are now more common in the British countryside than red squirrels, simply taking a small sample of individuals and then assuming the distribution of characteristics in that sample are the same for a given population. Whatever scientific sense it makes however, we have to ask why these statistically average characteristics make up such an ideal moral guideline by which to say what is, and what is not, constitutive of "normal" capacities for well-being, especially since many of these characteristics may be utterly divorced from our understanding of desire fulfilment or happiness. Indeed it is significant that in much of the literature on "illness" what Wakefield refers to as "harmful dysfunction" is categorized more as a matter of dysfunction, i.e. deviation from some sort of medical standard that may, or may not, be actually experienced, rather than being harmful, for instance, an organ may be diseased and thus experience a "lack

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[20] Ibid.

[21] K. Danner Clouser, Charles M. Culver and Bernard Gert.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

in functioning, however what effects this lack in functioning may have on a person's life may not be either apparent, or even identifiable, without some more direct symptoms of suffering as a related experience. Frequently Wakefield uses "chances of reduced life span" as a qualifier for reductions in functioning, even though such judgements would not be apparent until after a person's life has finished. Much of the literature on illness labours to decide whether benign tumours, or mild, age related sclerosis are in fact forms of illness or not. This is one reason I believe extending the concept of disability to cover those consequences of illness that may be characterized as affecting human well-being and desire may be an advantage in medical and social discourse.

As J.R. Lucas has noted, all humans are not equal with respect to their capacities for pleasure, the objects they gain pleasure from, and their freedom to do so.[22] The average I.Q. for example is held to be 100, i.e., this is the I.Q. which most closely resembles the scores held by the majority of the population.[23] Currently, a person is only held to be mentally disabled if their I.Q. is under 80. It would seem however, that given that there are some individuals with much higher I.Q. scores than 100, why should the fact that there are simply more people with an I.Q. of 100 than an I.Q. of under 80, make it legitimate to classify those with an I.Q. of 80 as being disabled and thus suffering? After all, those with an I.Q. of 100 could be said to be suffering from the point of view of someone with an I.Q. of 120, though they are not classified as such simply because they are more numerous.

Why, therefore, should simply being more common in any given population make a characteristic "normal" and thus a legitimate way of evaluating the capacity for well-being obtained from the possession of that characteristic? After all, if a person were to receive some sort of brain injury which lowered their I.Q. from 120 to 100, they would seem to have some justification in claiming that they have had something taken from them, even though from the medical perspective they have only become average rather than (in definitions such as Clouser's), actually disabled.

This question of statistical norms forming a legitimate evaluative basis for well-being is one of the underlying problems with the medical perspective which has motivated the formulation of the opposing social model of disability, which states (as Jones notes) that while individuals might be said to be impaired in some way, i.e. being blind, deaf, etc., the actual "disability", i.e. harmful consequence of any particular condition, is entirely a result of the majority's notion of "normal" and the prevailing social practices and prejudices which result from that majority view.[24]

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[22] J.R. Lucas, "Against Equality", *Philosophy,* vol. 40, no. 154, (Cambridge University Press, Oct. 1965), pp 296-307.

[23] For the sake of simplicity, I use I.Q. here as a proportional indicator of possible well-being, since it is both easily measureable, and has a well known average score, whereas other factors involved in disability, though still to some extent varying throughout a population do not have as quick and simple a measureable, salient characteristic. The actual relationship between general intelligence and well-being however is a much more complex matter, and one I will return to when I discuss the difference between conscious and unconscious disabilities in Chapter 2.

[24] R.B. Jones.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

In addition to considerations about the distribution of characteristics in a population, issues may arise when considering the nature and effect of the various medical conditions themselves on people's well-being. There may be conditions which have complex, discernible effects upon our well-being, either positive or negative, that are statistically abnormal, but due to not being universally negative are not clearly disabilities even though the negativity may be just as profound as with a disabling condition. Take, for example, synaesthesia, a condition which affects 10% of the population according to studies carried out by J. Gray.[25] A person with synaesthesia experiences one sensory modality in terms of another, thus, for example, when hearing a sound, a synaesthete might have an experience of colour (coloured hearing is the most common form of synaesthesia). In other cases a synaesthete may experience other senses in terms of smell, tactile sensation or even taste. According to purely statistical analyses, synaesthesia is not "normal" since it obviously does not affect a large percentage of the population, and in fact certain writers such as Richard Gray believe it to be a mental dysfunction, since it has been shown in experimental studies to slow down the synaesthete's reactions and abilities to recognize certain objects or written words.[26]

Ramachandran also reports some common characteristics of synaesthesia which affect a person's enjoyment or suffering in life directly, including a dislike of certain sensory stimuli, such as specific noises or tones, due to the way they appear to a synaesthete in his or her experience of them in another sensory modality.[27] One case, for example, involved a man with taste synaesthesia, who found certain words or phrases made him feel nauseous, particularly when in situations where his usual senses of smell or taste were required (as when eating a meal). It does not seem unreasonable to suggest that when this individual from Ramachandran's study was at a restaurant, his synaesthesia would preclude him from gaining as much enjoyment from the experience as an average non-synaesthete.

Synaesthesia is not however counted as a disability, despite the fact that it is statistically abnormal and has a definite and profound effect upon the synaesthete's life, causing the synaesthete to enjoy, or find unpleasant, a wide range of experiences. Synaesthesia is obviously highly individualized and what is unpleasant to one synaesthete may be pleasant to another, however, in cases where bad effects from the synaesthesia occur, it does seem to follow all the standard hallmarks of a medical disability (or indeed an illness), since it is both statistically abnormal and has a detrimental effect on the quality of life of the individual who has it. Statistical significance, or lack of, therefore seems to need to be tied implicitly to a notion of well-being, or how the "abnormal" condition has a noticeable effect upon the life of the person suffering it, however such accounts are rarely, if ever, found in medical discussions of disability, indeed commentators like Wakefield and Boorse simply

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[25]J. Gray et al., "Implications of Synaesthesia for Functionalism: Theory and Experiment", *Journal of Consciousness Studies,* vol. 9, no. 12, (2002), pp 5-31.

[26] Richard Gray, "What Synaesthesia Tells Us About Functionalism", *Journal of Consciousness Studies,* vol. 11, no. 9, (2004), pp 64-69.

[27] V.S. Ramachandran and E.M. Hubbard. "The Phenomenology of Synaesthesia", *Journal of Consciousness Studies,* vol. 10, no. 8, (2003), pp 49-57.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

dismiss the idea as that subset of illness which causes sensory or motor impairments.[28,29]

A further problem with the medical model and its assessment of the "normality" of certain conditions, as noted by Culver and Gert, is the fact that its classification of some conditions as disabling, particularly mental illness, has a basically subjective, and indeed somewhat cyclic quality.[30] Medically, a condition such as depression or paranoia is deemed disabling if it interferes with the "normal" functioning of a person. However, a certain amount of depression or fear is "normal" in experience of life. Medically therefore, such a condition is only counted as "clinical", and therefore a disability, when it either seriously affects a person's physical health, as in the case of anorexia, or their "normal" everyday functioning on a more general lifestyle based level.[31]

Even leaving aside the well known problem associated with the subjectivity of the diagnosing clinician in deciding whether her or his patient is functioning "normally" or is disabled, a further and more serious problem occurs when considering the criteria used to classify conditions such as depression as disabling in the first place, the problem of independent reference. As has been stated, in the medical model a condition is defined as "a disability" when it is statistically abnormal, and causes some sort of unusual amount of suffering. Given that anyone's life thought of in general terms will logically contain a certain amount of fear, depression, frustration, unfulfilled desires and other forms of mental or emotional suffering, beyond what point precisely can it be said that this suffering, even when apparently associated with a medical condition becomes such that it counts as a "disability", and therefore abnormal?

The usual medical practice, and that often adhered to in governmental legislation, is to set up some sort of average standard and assess whether a condition is disabling based upon this. This is often done with a crude tick box system, i.e. can an individual dress himself or herself, commute to work, cook a meal, drive a car, etc.? Thus when individuals were campaigning to have a condition such as M.E. (Chronic Fatigue Syndrome) classified as a disability, i.e. a condition which interferes with normal functioning, their only recourse was to detail the ways in which living with such a condition interferes with their functioning, and hope that the assessing authorities deem this to be abnormal, which is of course based upon the assessor's notion of what "normal" functioning is with respect to those activities, a fact which could be open to subjective or cultural bias. For example, a person with M.E. may be able to get out of bed, dress themselves and travel to work, but only after sleeping for 16 hours a day and doing nothing else with their time.

As J.R. Lucas notes, a condition such as chronic ugliness may have profound effects on a person's life, her or his interactions with others and inter-personal relationships,

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[28]J. Wakefield, "Disabilty and Diagnosis: should role impairment be eliminated from DSM/ICD diagnostic criteria?", *World Psychiatry,* vol.8, no. 2 (2009), pp 87-88
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[29] C. Boorse.

[30] Charles M. Culver and Bernard Gert.

[31] Stephen Tyreman, "It's Illness, but is it Mental Disorder?", *Philosophy, Psychiatry and Psychology*, vol. 14, no. 2, (June 2007), pp 103-106.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

especially compared to the point of view of someone with film star good looks.[32] When however, does a condition such as ugliness, depression, fatigue, anxiety or lack of intelligence count as disabling, as opposed to "normally" dysfunctional? As Jo Wolf notes, this very logic has been used by plastic surgeons to justify their occupation as a legitimate medical practice relieving a genuine life problem on a par with more conventional surgeons performing operations such as hip replacement surgery.[33] I will return to further questions of this sort in Section D when discussing disability and effort.

Such subjective medical judgements are only further complicated by the fact that the effects of some conditions are difficult to classify as entirely positive or negative. In the case of synaesthesia for example, defining whether its effects are good or bad seems a highly complex matter, since Ramachandran reports several beneficial aspects to synaesthesia, such as improved memory or musical understanding.[34] But even with traditional examples of conditions labelled as "disability," though the vast majority of their effects upon the individuals involved will be detrimental to their overall happiness, not everything is quite as one way as it initially appears. People with a visual impairment, for example, have been shown to often possess improved memory, spacial-orientation and increased auditory awareness. While it would seem incredibly insensitive to say that these possible benefits automatically qualify such conditions as not being in any way disabling, it does present a serious issue for attempts to define disability with any precision with respect to quality of life, since even the obvious effects seem far more complex in their relations to well-being than they might initially appear, thus a basic gross benefit/harm model, without making reference to what the harms and benefits actually consist of, will not be of much use in discourse.

In the medical model as has been outlined, the basic bad effect proposition for any statistically "abnormal" condition also seems problematic in the way that Clouser and others have argued, in defining precisely what form is taken by the harm or suffering which befalls individuals with disabilities, since "suffering" is such a hard concept to quantify.[35] There are some medical conditions, such as migraines, and the nausea of the synaesthete in Ramachandran's study, where some physically unpleasant sensation occurs, i.e. the experience of pain or discomfort. As Elizabeth Telfer and Derek Parfit note, such basic sensations of pain are indeed generally irreducible, and there is little need to enquire why any particular individual would wish not to experience such sensations since pain is, by its definition, unpleasant and something which individuals would always wish to avoid.[36] Though there are of course cases where people might trade off a certain amount of unpleasant sensation for some sort of benefit, such as going through an arduous exercise routine for the

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[32] J.R. Lucas.

[33] Wolff, Jonathan. "Disability Among Equals", *Disability and Disadvantage,* ed. K. Brownlee and A. Cureton, (Oxford University Press, 2009), pp 114-137.

[34] V.S. Ramachandran and E.M. Hubbard.

[35] K. Danner Clouser, Charles M. Culver and Bernard Gert.

[36] Elizabeth Telfer, "Chapter 1", *Happiness,* (Macmillan, 1980).

Also: Derek Parfit, *Reasons and Persons,* (Oxford: Clarendon, 1984).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

purpose of physical activities like playing sport or for increased fitness; such a trade off does not seem quite as plausible in cases of medical conditions which cause profound physical pain like migraines, since there seems little benefit to be derived from enduring such a condition. A moving example of this is the story of Johnny Kennedy, a lifelong sufferer of Epidermolysis Bullosa, (E.B.), a hereditary skin condition in which the slightest pressure or concussion causes the skin to blister, crack and become damaged, resulting in constant and excruciating pain.[37]

An opposing view of the status of physical suffering is offered by John Ozolins, who argues that profound experiences of suffering, such as that of victims of the Shoa (holocaust), give people the opportunity to develop very specific forms of courage, fortitude and moral virtue, and though certainly not pleasant or even helpful, and undoubtedly always to be avoided if possible, are not necessarily always absolutely bad for the individual who suffers.[38] Though it does seem to be true that individuals, like Johnny Kennedy, who live with profoundly painful medical conditions, have shown this level of outstanding moral courage, (indeed Johnny Kennedy's biography, detailing as it does his ability to gain enjoyment out of some aspects of life such as music and natural beauty, despite his constant pain, is held up as an "inspirational story of suffering") this admiration does not seem in any sense a legitimate basis to assess the value of suffering in general, still less the well-being of those who live with such suffering or the conditions that cause it.

While there are undoubtedly occasions where "tough love" or "being cruel to be kind" i.e. allowing another person to experience (or in certain cases, even causing someone to experience) some sort of harm in order that they attain a greater overall benefit might be a moral action, to believe that all suffering, and for purposes of the present discussion, particularly lives lived under medical conditions which cause extreme physical pain, should be treated in this way would seem to make such reasoning as Ozolins' meaningless, not to mention profoundly insensitive to the wishes and feelings of those involved, since though the sufferer themselves may personally have derived some insight or benefit from their suffering, to claim that such an insight compensates for that suffering (particularly when the claimant has not themselves experienced it), seems extremely tactless. It would also seem not to fully capture our admiration at those who have gained insights or happiness despite suffering, since if the suffering itself is merely reduced to the level of a method to gaining such insights, then all the sufferer has done is enacted a course of action working through the necessary steps to gain a predetermined goal, rather than gain that goal despite their suffering. Yet, it would seem that our intuitions would suggest that someone like Johnny Kennedy who was able to achieve a degree of well-being in his life in spite of the intense and constant pain his condition caused him, is far more worthy of respect than someone who achieves the same level of well-being without such suffering.

So there is little doubt that there are medical conditions such as migraines and E.B. involving the experience of physical pain or other unpleasant sensations, which cause the individuals who experience them to suffer denigration in their quality of life directly due to such irreducibly unpleasant sensations. Needless to say (given that most of us are lucky

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[37]*The Boy Whose Skin Fell Off*, Channel 4, 25 March 2004, Television.

[38] John Ozolins, "Suffering: Valuable or Just Useless Pain?", *Sophia,* vol. 42, no. 2*,* (2003), pp 53-77.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

enough to experience lives comparatively free from such levels of pain), they are also obviously "abnormal".

In the case of a "disabling" condition however, there is usually more involved than merely the experiencing of some kind of unpleasant sensation, and even in conditions such as E.B., it is not merely the fact that they are painful, even when the pain is long lasting and constant, that seems, according to our conventional usage of the term, to qualify them as "disabling". We do not, for example, regard an individual with some temporary painful condition which otherwise does not affect their well-being, such as a broken little toe, as being temporarily disabled in the same way an individual with a broken ankle would be temporarily disabled.

There are also obviously many conditions we do commonly regard as disabilities such as visual, auditory or motor impairments, where there may be no directly associated unpleasant physical sensation at all, so it is clear that the suffering involved in disability must be of a different category than simply the experiential. Conversely however, there are conditions regarded as disabilities such as migraines or chronic juvenile arthritis, whose chief defining characteristic is pain. In these conditions, it does not merely seem to be the fact that the individual experiences pain at intervals which legitimizes them as disabling, but that, as with a broken ankle on a temporary basis, the pain affects other aspects of their well-being such as their freedom of movement, experiences of pleasure and generally speaking ability to fulfil desires. A visually impaired person unable to read a newspaper is not experiencing pain, but they are experiencing a lack of freedom and a frustration of one of their desires, and while an arthritic person, who cannot hold a book in his or her hand for long periods without experiencing pain, experiences a similar frustration, it is the nature of that desire frustration rather than whether such a frustration involves pain that seems to be the defining characteristic of conditions that rank as disabilities, a factor I will discuss in more detail in Section C.

This distinction between the suffering caused by desire frustration and the suffering caused by pain may also be a defining factor in the differences between the scope of the terms "disability" and "illness", given that there are illnesses such as appendicitis which do not cause disability directly but may cause pain (though whether the pain might also be disabling is a matter I will return to later).

So the essence of what disability is, appears to involve conditions which may be in some sense abnormal, though in a fashion which cannot be quantified by a basically irreducible tick box system, but more importantly have complex effects upon a person's well-being that do not break down simply to irreducibly unpleasant physical sensations of suffering, but which may involve such sensations as part of their experience.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section B: The location of the bad effects of disability

As Jones notes, the term "disability" in its standard usage has an implicitly evaluative overtone.[39] It is not merely a description of an individual's mental or physical state, even in the way that describing a person as being in pain would be. It is, as stated in the previous section, a purposive term reflective of how life is lived, and (in Jones' opinion), a prejudicial one, implying that the individual involved is lacking something which most other humans possess, and, in the medical model, it is assumed that this lack automatically detracts from the quality of life of the disabled individual in some way. More specifically, followers of the social model of disability such as Harris or Newell argue that the medical model's categorizations of disabling conditions as automatically causing some sort of lack or diminution in the quality of what might otherwise have been "normally" happy lives, is itself extremely damaging for individuals who have those conditions.[40] Jones argues it is in fact a self-fulfilling prophecy that condemns those categorized as disabled to living less happy, broken lives, as they will have grown up with and internalized negative beliefs about themselves and their abilities to fulfil desires, and attempts to "fix their broken bodies" by members of the medical profession, as Shakespeare notes.[41,42] Writers working in the social model of disability are concerned with how the deficiencies in the well-being of disabled people's lives are a result of society's prejudicial beliefs and practices and the disabled individual's own learned beliefs about himself or herself and how these deficiencies may be alleviated by altering their beliefs, the perceptions which motivate them and the practices which result from them.

Thus, for the advocate of the social model, it is the overall conditions of society and its effects upon those categorized as disabled which are the cause of their inability to live an eudaimon life as easily as members of the non-disabled population, rather than something in the essential nature of the disabled individuals themselves. Several theorists working in the social model have noted thought experiments, or real life examples, about particular societies in which the effects of certain conditions on the quality of life of individuals who have them are reduced or negated altogether. Silvers, for example argues that in a society composed of paraplegics, all areas would be ramped, and thus the mobility issues associated with using a wheelchair would not occur.[43] Similarly, Koch notes the real world example of Martha's Vineyard, an island where 1 in 55 children was born deaf, rather than 1 in 600 as in the United States.[44] All islanders therefore made extensive use of sign language, thus profoundly reducing the communication and isolation issues normally implicit to deafness.

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[39] R.B Jones.

[40] Christopher Newell, "The Social Nature of Disability, Disease and Genetics: a response to Gillam, Persson, Holtug, Draper and Chadwick ", *Journal of Medical Ethics,* vol. 25(1999), pp 172-175.

  Also: John Harris.

[41] R.B Jones.

[42] Tom Shakespeare.

[43]Anita Silvers.

[44] Thomas Koch.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

While both lack of communication and mobility do appear to be things that would affect our well-being, establishing a similarity between these two issues under the single umbrella of "disability" does not seem quite as straight forward a task as the social theorist suggests. Since the experiences of people with different disabilities, for example a deaf person and a person with paraplegia, will be different, any accessibility related solutions to their respective conditions may be different, even diametrically opposite, such as would occur in providing information for both deaf and blind individuals. Yet the social theorist holds that, despite an often wildly different nature and effect, all these distinctions are entirely caused by, and can be corrected through, changes in social circumstances, and alterations in the judgements made about the lives of disabled people by society as a whole, "it is not their problem, it's society's problem": this assumption seems extremely strange, after all the fields of communication and mobility are vastly different areas of human experience, encompass very different activities, and involve very different social conventions and beliefs, since a person with paraplegia would have no problem speaking on a telephone and a deaf person would have no problem walking up a flight of stairs.

The social model, despite noting that "disabled" is a judgemental and not merely (as in the medical model), a descriptive term, does not actually broadly state an overall category for the deficiencies of well-being in the lives of disabled people, or how they differ from the lives of the non-disabled beyond claiming that those reductions in well-being have their source in social prejudice. According to the social model, these perceptions of difference and categorization are caused entirely by the attitudes of society and the beliefs in the medical model, and the majority of problems a disabled individual may in fact experience are mostly the result of these influences, and we should concern ourselves with the causes of the problems and not the problems themselves (Swain, Newell and Darke all express highly structured formulations of this view).[45]

Allan Colver in his international study (The SPARCLE Project), a study of the lives of children with cerebral palsy, concludes that it is "participation in the environment" which is the direct cause of such children's lack of aneudaimon life.[46] Thus it is the environment, on a physical, social and personal level which must be altered, not the children's physical or mental capacities themselves other than altering any internalized assumptions the children have picked up from that environment. Davis indeed, goes as far as claiming that society has an "ablest human paradigm", i.e. not just an environment, but an entire culture and pattern of thought structured around only those with "perfect human bodies"[46a]. It is also for this reason

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[45] John Swain, Sally French and Colin Cameron.

Also: Paul Darke, "Understanding Cinematic Representations of Disability", *The Disability Reader: Social Science Perspectives,* ed. Tom Shakespeare (London: Continuum, 1998), pp 181-198.

And: Christopher Newell.

[46] Allan Colver, *SPARCLE – The Study of Participation and Quality of Life of Children with Cerebral Palsy Living in Europe*, (Funded by European Commission, 2010).

[46a]H.J. Eysenck,*Race, Intelligence and Education* (London: Temple Smith in association with New Society, 1971).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

that the social model often draws parallels between disability and other forms of damaging social categorization and prejudice such as sexism or racism. However, it seems that the effects on well-being involved with disability are significantly different from those of being born of a particular racial group or a particular gender, and the types of strategy which both disabled and non-disabled individuals must employ in the name of equality are likewise of a far different sort. It took a change of law and attitude to alter race segregation on American buses in the mid 20th century, whereas allowing a person with paraplegia onto a bus would require physically modifying the buses themselves, not just the thoughts of the people who ride them and the laws that govern them.[47] Indeed, I have experienced this phenomenon myself, since even though in this country everyone has the right to vote in an election, the government still expects voting to be done in print, a medium that I, as a visually impaired person, cannot access. Despite the fact that there is no legal prohibition or other reason that stops me from voting, the nature of the physical environment itself and the existing process is what is prohibitive, and altering this prohibition would require physical, rather than simply legal intervention.

The social model, though also purporting to hold all disabilities under a unique banner of segregation, also fails to provide any answers in cases where the disability's effects on well-being are so profoundly personal that claiming any sort of social cause seems absurd, as in the case of clinical depression. Though there are undoubtedly allowances society could make in terms of work hours and pressure (not to mention an alteration in the negative overall judgements made against people with mental illness),[48] to reduce the detrimental effects of such a condition, the most profound effects will still be completely individualized, often felt entirely in private, and will once more be of a very different form from those experienced by someone with a physical impairment.[49,50]

There is thus no information in the social model on defining precisely what the detriments to well-being implicit in disability are, even though it is acknowledged that categorizing someone as disabled is in fact making an evaluative judgement about their well-being. As Shakespeare and Barnes note, disabled activists for the social model still discuss the more personal, and everyday occurrences of disability and its effects on their lives, "the aches and pains and urinary tract infections", behind closed doors.[51]

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[47] Many social model theorists draw analogies between disability and other forms of discrimination such as sexism, both Goering and Davis for example, however, while such comparisons are in some cases helpful, often I believe relying upon them too much misses fundamental facts about the nature of disability, for reasons I will discuss further.

[48] Thomas Szasz, *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct*, (first published 1974, republished by Perennial, 2003).

[49] Though a very few writers such as Chappell have discussed learning disabilities on occasion, very little is said by those working in the social model about mental illness, indeed, many writers seem to imply that it is another area of ethics entirely. In English law under the Disability Discrimination Act, however, mental illness is very definitely stated to be a form of disability, a view with which I agree entirely, (see Section D).

[50] Anne Louise Chappell.

[51] Colin Barnes, Geoff Mercer, and Tom Shakespeare, *Exploring Disability: A Sociological Introduction,* (Cambridge Polity Press, 1999).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Turning to the medical model itself, as noted in Section A, even in more explicit writers like Clouser, the specific nature of this lack or deficiency from normality is never precisely defined either.[52] Though, as noted above, saying someone is "disabled" is held to be an evaluative term, it is simply left up to our intuitions precisely why lacking a certain level of mobility, hearing, sight or various mental attributes like intelligence is automatically bad for us, just as it is irreducibly understandable why physical pain is bad. In medical circles, there is little point explaining why it is better to have full 180 degree vision than only 20 degree vision; this is held to be simply obvious. Just as we would not ask why it is necessary to treat a painful infected abscess, we should automatically also attempt to correct any disabling condition (a contention which has often been challenged by writers in the social model).[53] Thus the statistically normal, average or above average on all tests individual, free from physical pain is, according to the medical model, a potentially ideal standard of well-being. Social theorists would again challenge this as simply another prejudice similar to the Nazi belief that being part of an "inferior race" produced a worse overall quality of life, and indeed several Nazi doctors during the Shoa conducted research supposedly aimed at instilling Aryan characteristics in non-Aryan people, though of course not with the view that such characteristics would improve the lives of the people who had them.

As noted earlier with relation to the deaf person and Mozart, however, the relationship between having a "normally" functional body and well-being does seem to be in some sense a legitimate one rather than an artificially created ideal whose effect on well-being is purely due to the prejudices of people who possess it, such as the Nazi view of the perfect Aryan. Even if this intuition of a perfect standard to which we can compare "disabled" people is more than a prejudice, it may however not be quite as clear cut as medical theorists would have it. There are several things, even things as integral to our bodies as eyes, ears, and nerves, that we may happily do without and yet would not experience any noticeable change in our well-being: our appendix (once used to digest cellulose in our evolutionary past but now completely dysfunctional), our tonsils, or several pints of blood for example. The obvious difference between these items, and our limbs, sensory organs and mental faculties seems to be simply one of noticeable effect.

It would be quite possible to have such integral body parts as our appendix or tonsils removed secretly without our notice, indeed as shown in Section A, saying how a diseased organ which has no effect directly on the person's actual well-being is a major problem in the definition of illness, especially for writers like Wakefield who appeal to "evolutionary function" rather than eudaimonia. Were any unnecessary, dysfunctional organ such as the tonsils removed, we would only be able to find out about such a lack by having a specialist perform some very specific tests such as a C scan for an appendix, or examination with a laryngoscope for tonsils. Though obviously there are issues surrounding privacy and bodily integrity involved with any sort of surgical procedure, it does not seem reasonable that we

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[52] K. Danner Clouser, Charles M. Culver and Bernard Gert.

[53] Lynn Gillam, "Prenatal Diagnosis and Discrimination Against the Disabled", *Journal of Medical Ethics,* vol. 25, (1999), pp 163-171.

[54]Gerald L. Posner and John Ware,"Mengele: The Complete Story", New *York: McGraw-Hill*, (1986).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

could object to the inadvertent lack of an appendix or tonsils in and of themselves, since there are no ways in which they may contribute to our well-being positively, (though they may of course have a negative effect by becoming infected).

So the first and most obvious point appears to be that disability must have a detrimental and noticeable effect upon our well-being in some way. Like our appendix, however, disability appears to be dependent upon intrinsic states of a person's physical or mental self, rather than the actions of others or entirely external states of affairs. If, for example, I lose all my money in a robbery, I no longer possess the money, am not free to use it in ways that increase my well-being, and may suffer many forms of unpleasantness, such as calls by debt collectors. I have been unfortunate and unlucky, but am I disabled?

Though the money was undoubtedly possessed by me, and lacking it causes detrimental effects on my well-being, the money itself was not in any sense integral to my physical or mental self. Even if it was my entire life savings that were stolen, and lacking them will have a profound effect upon my life, it still does not appear appropriate to say I have been rendered "disabled".If however the burglars, for some reason of their own, rather than stealing my money stole some part of my body, for example a hand or eye, I would then have been disabled since what was taken was intrinsic to myself.

On the other hand though, there do seem to be parts of myself which, though solely and uniquely mine and not able to be stolen separately like money or possessions, relate exclusively to the judgements and interactions of others: my hair or eye colour, how physically attractive I may appear, what accent I speak with, even, to a considerable extent, what racial group I belong to. Though all of these characteristics are as fundamentally intrinsic to myself as sight, hearing, etc, their relationship to myself, my abilities and my perception by others in society at large, seem rather different than the more basic relationship of having two hands, two eyes, two legs, working muscles and so on.

Perhaps a possible acid test for whether something may or may not count as a characteristic which could be the bearer of "disability" could involve a thought experiment. In his novel *A Connecticut Yankee in King Arthur's Court,* Mark Twain imagined a man who was, through an unknown agency, transported from 19th century America, to 6th Century Britain.[54] This cast him out of all social context and made facts such as his accent, social position, possessions and wealth, completely inapplicable to his new circumstances.

Obviously, since he was still in a formal society, certain things, such as his male gender, did in fact still have a great impact upon how he was treated. If however we take Mark Twain's notion of a person taken entirely out of all social context and relation to others and institutions, to an even greater extent, perhaps exiling our own castaway to some desert island in the distant past before the evolution of humanity or to some barren planet devoid of life, this may provide us with a useful test of an individual's characteristics. By asking whether any given characteristic ceases to affect the castaway when they are removed utterly from all social context and the judgements of others, and what it may be possible for the castaway to do, or not do, alone in exile with respect to fulfilling his/her desires and

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[54]Mark Twain, *A Connecticut Yankee in King Arthur's Court,* (first published 1889, republished Simon & Schuster, 1997).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

improving his/her well-being (a matter I will return to in the next section), we have a way of determining what characteristics and capacities of the castaway are dependent entirely upon their social setting, and what are internal to the physical or mental self and thus fitting candidates to count as possible sources of disability.

Though this criteria for establishing the limits of disability may at first sight appear to side with the medical model's view of disability as the possession of a "broken body", it should be noted that merely saying that disability should be considered as being involved with the characteristics of the mental or physical self, is not to say that the harm caused by disability is always and only ever directly caused by these characteristics alone, and not society's perception of them, or practices surrounding individuals who have them.

After all, it is trivially true that were a victim of racism not of the race against which a prejudice was held, their well-being would be unaffected by it. The fact that they are of that race is intrinsic to them, and would not change were they in a different social setting, however it is the beliefs and actions of the racist society which causes this characteristic to become a cause of suffering, not the fact that a person has the physical characteristics of belonging to the race in question. Thus, a person who is dark skinned will remain dark skinned wherever they live, but the significance of this fact will alter according to how such a physical characteristic is perceived by the society in which they live.

In the case of a victim of class prejudice however, if the social setting were changed, for example by the person going to a less prejudiced society, they will not only no longer be experiencing prejudice, but the very characteristic which made them a member of the prejudiced group in the first place will no longer exist. The person will no longer live on "the wrong side of town" or speak with "a lower class accent" since both of those things exist only within the society that holds the prejudice.

On the other hand however, a person suffering one of the above mentioned conditions such as migraines or E.B., would seem, even before we consider whether or not conditions are disabilities, to already possess characteristics internal to the self which naturally result in a loss of well-being via increased physical pain, irrespective of any other factors, social or otherwise, a case which might also prove true for other forms of impairment. Thus, while the attitudes, practices and judgements of a society may certainly have an effect upon a disabled individual, it is wrong to assume that the disability is in itself constituted only by that effect, since the primary cause of the disability and at least some of its effects upon well-being are internal to the person's self (either physically or mentally), and would still exist even when considering the person in utter isolation from society.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section C: Disability, desires and capacities for well-being

In the previous two sections, we have established that disability is a noticeable condition intrinsic to a person's physical or mental self, which detrimentally affects their well-being. This detrimental effect might involve extra social elements and judgements being made about a person, but is not entirely caused by society, and may be related to some condition of a person's physical or mental self not shared by the majority of the population, but is not merely identical with such a condition. But if the harm done to an individual by a disabling condition may not be purely reduced to either of these factors, what exactly is the nature of this harm?

As noted previously, "disability" is both a purposive and judgemental term. When used of a human it appears to carry both the implication that that person is unable to fulfil some kind of purpose in his/her life, and that such a lack is a result of the intrinsic state of that person's basic nature. In a more literal sense, many disabilities, as noted by several theorists working in the social model such as Newell, reduce down to negative statements about a person's deficiencies from what they deem to be perceived norms.[55] Thus, a person is judged as "deaf" because they cannot hear, as "blind" because they cannot see, as paraplegic because they cannot enjoy a full range of movement, etc.

In the social model of disability, such judgements themselves are automatically assumed to be a result of society's and the medical profession's prejudiced view of what an ideal human should be, but there does, as noted earlier, seem to be some merit to the idea in its basic, definitional sense, in that a person experiencing paraplegia, simply by virtue of possessing paraplegia, does not have a full range of movement. As noted previously, these various lacks must have a noticeable effect upon the person who experiences them, and more specifically upon their well-being.

One recent example which might give an insight into the nature of these effects upon well-being, is that of the rugby player, Dan James.[56] In 2008, Dan James campaigned to be euthanized after receiving a spinal injury during rugby training which left him completely paralyzed.[57] In an interview given to *The Guardian*, his parents stated that being paralyzed had removed all of the things, such as sports and travel, which Dan James had previously taken pleasure in from his life. They freely admitted that other people have been able to experience incredibly happy and full lives with such a paralysis as Dan's, but that a life of the type those people enjoyed, focused upon activities vastly different to those Dan had gained pleasure from previously, not to mention that the increased amount of dependence upon others which such a life would entail, had no appeal or value for Dan.

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[55] Christopher Newell.

[56] Robert Booth, "'He wasn't prepared for a second class life': why injured rugby star went to Switzerland to die", *The Guardian*, 18th October 2008. Available at: https://www.theguardian.com/uk/2008/oct/18/11

[57] It is not my intention here to embark upon a debate about the general moral status of voluntary euthanasia on the part of disabled individuals, merely to examine the factors which Dan James considered in making the decision to end his life, factors implicitly tied up with his well-being and with his disability. Full discussions of the status of euthanasia, including euthanasia in cases such as that of Dan James have been made by many commentators, and though some aspects of that discussion are related to an examination of disability, many of the key considerations, such as the need to think about whether any condition is terminal, are not.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Thus, when Dan evaluated his life with paralysis as not worth living, this decision was motivated purely and simply by the disparity of the contents of that life, and how they measured up to Dan's expectations of what he wished his life to contain, i.e. his desires. Thus, to take a single example, while Dan desired to play rugby, since constituents such as possessing the ability to run, throw a ball, etc., would seem to be necessary attributes which a person must possess in order to fulfil the desire to play rugby, attributes which would be unavailable to a person (such as Dan) experiencing quadriplegia, the desire to play rugby is one which such a person could not fulfil. Whether in fact these "necessary" conditions of fulfilling a desire to play rugby are precisely necessary, and the ways in which activities, states or actions might be altered is a question I will return to later in Chapter 3, since it relates to a critical question in disability, that of accessibility.

Dan was seemingly left with desires which it was not possible to fulfil, a type of desires which, as Griffin, Noggle, and many other commentators note, will inevitably have a negative effect upon our well-being.[58] Whether Dan's response to this problem of a life filled with impossible desires, ending it, was a reasonable one is far beyond the scope of what I'm trying to achieve here, and would in any case seem to be a decision best left up to Dan himself.

For the purposes of the current discussion, Dan's example serves to illustrate that at least part of the harm involved with disability is related to both the desires of the individual with a disabling condition, and the mechanism by which the disabling condition frustrates the fulfilment of those desires. Identifying the harm of a disabling condition however, simply by stating that it frustrates certain desires, needs some clarification.

Firstly, and obviously, as Newell notes, many disabled individuals do in fact live full and happy lives without significant loss of well-being caused by frustrated desires.[59] Such people would have (in the terms of many commentators on desire theory) adapted their desires to suit their circumstances, and thus avoided the pain of unfulfilled desires.

A totally deaf person (as noted earlier), being biologically unable to appreciate Mozart, would seem to be better served in their well-being by not having a strong desire to do so, and thus avoid a significant loss in their well-being as a consequence of an unfulfilled desire.

This claim does indeed seem legitimate, since to attempt to assign any sort of desires to be "normal" onto a disabled individual would seem to be both dangerously close to the "normal is ideal" thinking of certain forms of the medical model, and also, in most cases, simply untrue according to the actual views expressed by disabled individuals themselves. In fact as Sobel notes, a significant component in someone achieving well-being via the

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[58] J. Griffin.

Also: R. Noggle, "Integrity, the Self and Desire-Based Accounts of the Good", *Philosophical Studies,* vol. 96,(1999), pp 303-331.

[59] Christopher Newell.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and
its Practical Uses in Everyday Life

By Luke Hewitt

fulfilment of desire seems to be the practical wisdom to distinguish desires which are possible to fulfil from those which are not, and thus as far as possible minimize the pain felt from possessing unachievable desires, by discarding such desires in favour of those an individual is more likely to attain.[60]

Equally however, our intuitions would seem to imply that a disabled individual, even one who does not feel the desire to engage in activities which they do not, due to the circumstance of having a disabling condition, possess the necessary attributes to undertake, has still suffered some sort of harm. This is borne out by the fact that while many disabled people who are actively biologically unable to appreciate something may be at the least curious about it, many people blind from birth, for example, while they could not be said to "miss" seeing colours, still maintain an active curiosity about the sensation of seeing, especially given our common sight based language. Of course such a curiosity varies between individuals, but that it exists at all still seems to suggest that even when an active desire is not felt as a detriment in a person's life there is still a lack; I personally always feel sorry that with my level of vision I will never understand or be able to respond to facial expressions.

It is also true that the vast majority of desires have a varying list of requirements to fulfil, and most of the time a disabled individual will tend to fulfil some, rather than none of those requirements, as in the case of a blind or deaf person wishing to watch television which, despite the use of the verb "watch", contains both audio and visual elements, or a person with paraplegia's desire to play table tennis where they are quite capable of using the bat and apprehending the ball's position, but unable to move swiftly around the table in order to hit it. In these cases, the idea that a disabled individual has experienced the harm of an only partially fulfilled desire seems quite legitimate.

Some more radical theorists, such as Germon, in the social model have suggested that the very idea a disabled individual is "suffering" other than via social factors such as direct exclusion to use buses, etc. is itself prejudiced, but this does seem distinctly problematic.[61] This can be seen if we compare a disabled person's biological restrictions in fulfilling some categories of desires to another type of restriction, a political one.

Suppose we consider a restriction of travel. It is, of course, perfectly possible to live a full and happy life without ever leaving the British Isles, and there are undoubtedly many people who do so. It would however, still be regarded as a great moral wrong if the government decided to close its borders, and not allow anyone to leave the country. Such action would require a very good justification, such as an extreme state of emergency like a desperate war or natural disaster, and the public would certainly expect such a restriction to be lifted once the crisis had passed. The argument that "nobody needs to leave the country to live a happy life" would hold no water at all, and in fact would be regarded as a frighteningly authoritarian one reminiscent of Orwell. Another factor of such a governmental decision is that it would be thought of by most people, (especially political commentators) as a universal wrong, whether the population agreed as a whole or not, since freedom is frequently

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[60]D. Sobel, "On the Subjectivity of Welfare", *Ethics,* vol. 107, no. 3. (1997), pp 501-508.

[61] Penny Germon, "Activists and Academics: Part of the Same or Worlds Apart?", *The* Disability *Reader: Social Science Perspectives,* ed. Tom Shakespeare, (London: Continuum, 1998), pp 245-255.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

considered such a basic human necessity. Even if people brought up in a country with such a direct ban on travel were to claim it as reasonable, the majority of ethicists would disagree. Yet such restrictions pertaining to travel, either fully or in part, are placed on the shoulders of those with mobility related conditions, simply because of their possession of such conditions.

What seems to be the common evil in all these cases, whether travel, playing table tennis or restriction of desires in general, is the fact of curtailed freedom of choice. In the case of a disabled person, whether or not they possess a desire whose accomplishment they are biologically restricted from seems to be only a question of how adaptable to circumstances they are and, to an extent, pure dumb luck in what desires they possess (had Dan James been an author instead of a rugby player, quadriplegia would have had far less effect on his desires). In terms of classifying their disability, what seems to be the important factor is their capacity to engage in certain activities which either form the inherent constituents of desires, such as a person with paraplegia's inability to play rugby, or are directly identical with the desires themselves, such as a totally blind person's inability to appreciate portrait painting.

These capacities for well-being therefore, represent those conditions or actions which a disabled person is unable to perform due to their disability which restrict the amount of choices of desires they may fulfil, or activities they may engage in. Of course, such capacities must actually affect well-being directly. An inability to roll the tongue for example would not seem to have any direct effect upon a person's well-being, since there seem to be no situations in which it may come into play or desires it might affect. Of course, as social theorists claim, all too often the extent to which any given desire or activity relies on its constituents which may be restricted to a person without a particular capacity is entirely a social matter, i.e., society often sets the boundary conditions for carrying out certain actions or attaining certain goals. Thus (as Silvers notes), if all buildings had ramps, a person with paraplegia's desire to go up stairs would not be reliant upon a capacity to walk.[62]

However, trying to categorize all desires in this fashion seems to be too broad a distinction. Firstly, there do seem to be desires and constituents of desires whose nature and fulfilment is not in fact dependent upon social factors at all. One of these might be a person with quadriplegia's decision to pick up an object not within their reach. There are accommodations and alternatives which society might make to afford the person with quadriplegia ease in carrying out desires, such as providing professional assistance or technology which can be operated by the person like a computer with an eye tracker to enable use of a mouse, however the basic desire of a person with quadriplegia to independently reach for and pick up an object under their own volition seems related to only the person themselves, and their individual desire to enjoy the experience of freedom of movement, and not for any value placed upon this experience by society as a whole, (I will discuss the question of assistance further in chapter 3).

As J.R. Lucas observes, we are not in fact all equal, and thus there may also be cases where a person lacks a certain capacity, but normally would not be considered disabled.[63]One

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[62] Anita Silvers.

[63] J.R. Lucas.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

of these is allergies. While a person with incredibly serious allergies may in fact (according to certain legal or tick box based definitions), count as disabled, a person with perhaps only one allergy would not seem to be. Someone for instance with an allergy to honey would seem to have certain dietary restrictions which prohibit them from eating some foods, but in comparison to someone with a gluten or lactose intolerance, the amount of food they could not choose to eat would be comparatively small, thus commonly in medical circles an allergy to honey is not considered a disability. I would argue however, that such a condition should in fact be counted as a disability simply due to the biological restriction it places upon a person's desires, even if not a serious disability by virtue of this restriction applying to comparatively few possible desires, and thus requiring far less desire juggling to accommodate with aneudaimon life.

This idea of disability as gradable, is much at odds with the social model which sees "the disabled" as a specifically defined social grouping such as "blacks" and thus similar to racism, rather than a condition with varying degrees of severity and effect, (though I will return to the idea of the commonly categorized "disabled" rather as a distinct group and the bearers of prejudice in chapter 4). However, a similarly broad set of characteristics used to identify disability is found in the World Health Organisation's classification, which characterizes disabling conditions by a deeply complex and highly stratified structure of the aspects of life and general health they have an effect upon, including dietary restrictions and indeed the possible prejudices of others (in fact, the W.H.O. criteria for a disabling condition does attempt to reconcile both the social and medical models by this system).[64]

Of course, possessing the ability to see, hear or move freely are heavily involved in both the constituents and general form of far more desires than merely the ability to eat honey, and so the lack of these should indeed be recognized as appropriately more severe. Therefore it seems safe to suggest that the "lack" of a disabled person is not simply a lack of sight, hearing, etc, but a lack of the capacity to enjoy or experience fulfilling desires some or all of whose constituents depend upon personal characteristics affected by the internal condition of the self. Thus the harm done in these cases is as much a loss of freedom as that experienced by people living under any other enforced restriction of desires.

There are however, many conditions which may need to be considered as disabilities but which do not seem simply to place a blanket restriction upon some classes of desires. What desire for instance is directly restricted by the intermittent pain of a migraine sufferer, the fatigue of someone with M.E., or the suffering associated with chronic depression? One could argue, as in fact Culver and Gert have, that such conditions contravene a basic desire to live a life free from pain.[65] This however seems entirely inadequate, both because it is deeply unspecific, and because, by the very nature of life in general, everybody will experience this desire and have it unfulfilled. Therefore, a more subtle and adaptable schema for the types and nature of desires which disabling conditions frustrate would seem to be necessary.

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[64] "Towards a Common Language for Functioning, Disability and Health", *I.C.F.* (World Health Organisation, 2002).

[65] Charles M. Culver and Bernard Gert.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section D: Disability, effort and time

The basic freedom/desire/fulfilment model outlined above, though perhaps of use in defining the activities and goals which may or may not be precluded from a disabled individual, does however miss a key factor in its application to disability; a lack which many individuals who live with disabling conditions will note immediately and one which is intrinsic to the definition of certain conditions, this is the issue of effort.

As noted earlier, breaking the distal phalanx of the toe (the bone right at the tip), does not, simply by virtue of being painful count as disabling. The basic sensations of pain the person experiences, though undoubtedly severely unpleasant would not, in and of themselves be sufficient to cause a disability, and we would assume that someone with a toe broken in such a way would be completely free to satisfy their usual course of desires, as there seem few desires for which having ten whole and functional toes are a necessary constituent.

Needless to say, were the toe broken at the proximal phalanx (near the foot), or were it a broken ankle which would make walking physically impossible, then it is easy to see how a wide range of activities, all those associated with mobility and freedom of movement such as walking, dancing or even just preparing a meal while standing, would be detrimentally affected.

Suffering a broken distal phalanx however, walking would be entirely possible, but only with a significant and noticeable amount of constant physical pain. Under these conditions, a person might well change their lifestyle in several ways to avoid the pain of walking: utilizing more public transport; allowing more time to travel between places so as not to have to walk more quickly and thus intensify the pain; directly refraining from activities involving the feet such as cycling not because they are physically impossible to perform, but because the pain they cause is of such a magnitude that it negates any rewards of pleasure, extra mobility or physical fitness which a person might gain otherwise. Also to be considered in such a lifestyle change, there is the large amount of time the person would have to spend resting from the general strain they put on the broken bone by carrying out unavoidable, everyday walking and standing like basic movement around their home or workplace. In this case, though the person's ability to walk is not directly compromised in the way a person with paraplegia would be, the sufferer of the broken toe has undoubtedly felt a distinct lack in the usual fulfilment of any of their desires for which walking is a necessary component, a lack directly attributable to the intrinsic condition of their body.

Of course to a large extent their usual desires may in fact be performed, but at a far greater cost of time, pain, and physical exhaustion than they would have been with ten unbroken toes. For example, regarding a journey to and from a place of work, the broken toe sufferer may have to set off significantly earlier, since what previously might have been a five minute journey is now a fifteen minute journey, and more exhausting over all due to constant pain and the necessity to walk in an awkward, unfamiliar way that tires the muscles.

It is likely that the person in question would not actually change his or her job to one closer to home (even assuming that opportunity was available), but rather simply live with the increased amount of time, fatigue and pain spent on such a journey. Thus, though not having actually suffered a frustration of their desire to perform the job in the same way, being

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

sacked, or being totally unable to attend work would frustrate that desire, the cost taken to fulfil that desire has increased significantly as a direct result of the injury. So, in addition to the impact upon their desires directly related to walking, there is also the need to rest the broken bone while it heals, and make accommodations for the increase in time and physical work involved with walking. There might also possibly be the need to actively alter desires as well. For example, a person interested in sports such as football or tennis may have to preclude themselves to a passive interest as a spectator, rather than being a participant.

It is worth bearing in mind that, unlike Dan James, mentioned in the previous section, a person suffering a broken toe does indeed still have all the physical prerequisites required to play football, the ability to run, kick the ball etc., but only at what would be an extreme cost of effort, pain and (quite possibly, risk of further physical damage).[66] We would generally hold such a cost to outweigh the benefits of playing football, even from the perspective of the most avid footballer, and, as Griffin notes, were someone expressing such a desire we would probably wish to dissuade them on accounts of the cost being "too high".[67] This effort factor, not merely the ability or inability to carry out certain desires but the accumulated cost of fulfilling them, is one of the most defining characteristics in the actual experience of everyday life with a disability, and thus is absolutely central to the practical effects of disabling conditions on the quality of life of individuals who have them.

To further clarify this notion of abnormally increased effort, it is only necessary to look at conditions which are classified as disabilities not because they cause the actual inability to fulfil desires in the same way as paraplegia, blindness, etc. may biologically preclude the carrying out of those desires or the constituent parts of those desires, but because of the heavy toll they exact upon the price of any desire fulfilment. As noted in the previous section, most obviously this applies to conditions such as M.E., migraines, chronic insomnia and other neurological or psychological conditions, where very real and obvious exhaustion, physical pain or involuntary lethargy limits the freedom of an individual to carry out his or her desires. However, in various psychiatric resources, such as the *Dictionary of Psychiatry*, the severity of conditions like depression or paranoia and their status as "chronic" is directly related to the impact they have upon a person's life and "normal" functioning, i.e. the effort costs required to fulfil the sufferer's desires.[68] Thus while everyone feels depressed at certain points in life, the psychiatric profession only holds such depression to be "chronic", i.e. categorized as a disability, when it interferes with a person's "normal" functioning and ability to pursue everyday interests. Though, as noted previously, there is still a significant question in what "normal" effort is, a matter I will return to later, it does seem significant that "effort" is given as the chief defining characteristic of certain disabling conditions, even when the definition of those conditions cannot be tied directly to the malfunctioning of a sensory apparatus, or other human capacity.

As noted in the previous section, a similar methodology is used by the World Health Organisation in characterizing disabling conditions, by establishing a large and many-layered

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[66]Robert Booth.

[67] J. Griffin.

[68] H. Thakurdas, *Dictionary of Psychiatry,* (Springer, 1979).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

tree of effects, then seeing how many and which of those effects a given condition involves.[69] Many of those effects involve the degree of time, fatigue or pain carrying out certain common life activities involves, even when such activities may be undertaken at all.

It is easy to see how a person with chronic depression, while physically able to fulfil other desires, does not have the mental energy, drive, or necessary mood to do so, as a direct result of their condition. Thus, the commonly voiced complaint "It's an effort to get out of bed in the morning" seems to have a very literal and practical meaning in its impact.[70,71,72]

Equally, as noted previously, the characteristic disability caused by profoundly painful conditions such as arthritis is not merely the fact of the pain itself, but the ways pain, both directly and through exhaustion caused by the necessity to constantly endure it, makes a range of desires, while not as obviously physically restricted as those of a person with paraplegia, unusually difficult, i.e. costly in terms of effort, to perform.

Despite being very much prevalent in the lives of disabled individuals, this factor of effort is one which has received little to no attention from ethicists. Those working in the social model, seem more concerned with absolutely restricted desires than the effort involved in carrying out unrestricted ones, and while medically it is recognized that certain conditions are characterized by the extra effort they impart to everyday life, the full extent of the issue, as well as any theoretical attempt to quantify it under any sort of rigorous definition of disability has not received as much attention as perhaps it should. Possibly this is because it is an issue which the social model, with its emphasis on social change as a way of accommodating disability, finds difficult to accept, and part of "the aches pains and urinary tract infections" which advocates of the theory prefer to ignore.[73] If indeed, as Silvers wished, ramps were used instead of stairs in all locations, there still remains the less easily solved problem that it is generally considerably more tiring to push a wheelchair and its occupant up five floors worth of ramps than it would be to walk a similar amount of distance on stairs, a problem whose nature it is less easy to attribute to the lack of ramps in society.[74]

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[69] Towards a Common Language for Functioning, Disability and Health.

[70] Though there is a long running and wide ranging discussion, following theorists such as Brülde, about the question of whether the practice of pathologizing certain psychological conditions is itself merely another prejudice, this objection is not based upon effort, but on differences of perception of reality.

Here, my main concern with such conditions is not whether a person with paranoia's beliefs are true or false, but how much impact the anxiety and fear caused by such beliefs have on their life, a much less disputable claim. While there are certain conditions of purely altered perception whose effort cost is far less obvious, such as those outlined by Culver and Gert, whether these fall under the auspice of "disabling conditions" i.e. conditions intrinsic to a person which cause detriments in well-being, is a matter of considerable debate, and one which I will partially return to in discussion of "unconscious" disability in the next chapter.

[71] Bengt Brülde, "Mental Disorder and Values", *Philosophy, Psychiatry and Psychology*, vol. 14, no. 2, (2007), pp 93-102.

[72] Charles M. Culver and Bernard Gert.

[73] Anita Silvers.

[74] Anita Silvers.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Part of the reason the problem of effort is such a major one in the field of disability, (and one which must be addressed), is its wide ranging application. Not only the above examples of pain, fatigue and lethargy, but also more commonly recognized disabling conditions such as blindness, deafness or restriction of movement have their share of desires whose attainment is characterized by increased amounts of effort.

Imagine for example the act of catching a train. A person using a wheelchair must specifically request, often at a significant time in advance, that a ramp be provided both onto and off the train. This then requires them to submit to the ministrations of strangers since it is not something which they could do independently, they would also need to arrive at the station much earlier than non-disabled passengers in order for such arrangements to be made, and are therefore very unlikely to be able to purchase a ticket instantly at the station; often the lives of disabled people are sadly lacking in spontaneity. It is also worth noting that a disability access service such as assistance onto the train can vary wildly in quality depending simply upon the people involved and how efficiently the service, even when one is in place, is applied. (I will consider the quality of human assistance more completely in Chapter 3). A person with paraplegia is also unlikely to be able to use station facilities such as toilets, and could only make use of cafeteria or shopping facilities at the station or on the train if certain spacial and mobility requirements were met, which again is something that is heavily subject to variation.

Someone with a visual impairment must either also make a request for assistance in finding and boarding the train (requiring similar amounts of preparation and interaction with and reliance upon strangers), or otherwise have sufficient skills in mobility techniques and memory of the station to do so, which could easily be disrupted by a change of platform, addition of barriers, sign boards or other unexpected moveable obstacles it would be necessary to manoeuvre around. Such skills would also need to be attained over a period of time with a large amount of route learning, again necessitating a large amount of preparation, and even then could be disrupted by alterations in the train times, rerouting through a different platform or the loss of an auditory announcement, (all of which have caused me to miss trains in the past). It is also worth noting that the visually impaired individual does not merely have to locate the train itself, but also the ticket office, (even if the station provides assistance this would be necessary), toilets, or any other desired facility, not to mention finding a seat after boarding the train.

A person with hearing impairments is not only at the mercy of auditory announcements which they could not access, but also is required to lip read, in order to buy their ticket or ask for information, a process taking significant concentration and open to variation in factors such as lighting conditions and the readability of the ticket seller's lips. There is also the necessity of communicating desires to buy a ticket, etc. to individuals with normal hearing, which presents its own range of problems owing to the speech and communication issues inherent in deafness, and of course such difficulties will also occur on the train as well if, for example, the deaf person needs to discuss their seat reservations with the guard.

One proposition in establishing a possible acid test for effort might be to return to the naked, possibly disabled, castaway exiled from society mentioned in Section B. Would it,

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

given all relevant information, be more or less difficult for said castaway to perform any given activity with intrinsic disabling conditions, and if so, how much more difficult? (I will return to this question in the next section).

As noted in Section C, it does not seem to matter if the disability is related to only a small range of activities, for instance a person with a specific phobia may require significantly more mental effort and fortitude when attempting activities related to their phobia but be otherwise unaffected by it.

There is also the fact that in the case of many activities, such as the communication of the deaf individual or the assistance requirements of some visually impaired or paraplegic individuals, the degree of effort involved in carrying out any given activity or fulfilling a range of desires can be very heavily influenced by social factors and the adaptability of the environment, even though, as has been stated, it is not these environmental or social factors which in themselves seem to constitute disability since they are external to the self. It is also worth noting, that however much adaptation is made, the overall costs in terms of effort for a person with a disabling condition may rarely, if ever, be reduced to a point of non-existence. For example, as noted earlier, even if all access ways had ramps, more physical effort in terms of propelling a wheelchair up a ramp would still be required as compared to climbing stairs.

One of the more severe issues concerned with effort as a criterion in disability definition is its unspecific nature. Being that effort works on a sliding scale rather than a basic all or nothing premise the way fulfilled or unfulfilled desires do, it presents a far more difficult problem in terms of quantification. As noted when discussing the medical model's use of gross statistics to attain normality, not everyone is equal.

To return to I.Q. (which, while theoretically problematic does have the significant advantage of being quantitative, thus providing good example matter), a person with an I.Q. of 100 would take considerably more effort in formulating quantum physics calculations than someone with an I.Q. of 120. However, someone with an I.Q. of 80 would similarly be disabled when calculating the amount of money necessary to buy items in a shop. Unless we follow the statistical model, there is no practical difference between these two levels of effort or these two sets of activities, given that both individuals desire to carry them out, and no way of saying that either is more or less disabling than the other.

For this reason it is necessary to readdress in detail one of the other most basic and commonly discussed concepts of disability theory, and one which both the social and medical model have expended much time in exploring: the concept of normality.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section E: Normality and environmental fitness

As noted previously, there are considerable problems with definitions of normality as applied to individuals, or even as used to categorize disabled as a distinct class from non-disabled. We have established a disabling condition as one which is intrinsic to the self and causes either a direct restriction upon fulfilling desires or an abnormal amount of effort required in their fulfilment. It is therefore necessary to actually define what a "normal" amount of effort required to fulfil a certain desire is, and also precisely in what ways the need for this "abnormal" effort distinguishes disabled individuals from non-disabled ones.

Gross majority based definitions of normal appear to run into severe problems with bias, environment and equality, still more so when the object to be considered is not the individual themselves but the amount of effort those individuals must put into fulfilling a certain desire. Thus, as previously noted, to people with differing physical or mental capacities, the fulfilment of desires will require different amounts of effort. So, lifting and walking with a 25 kg suitcase, performing basic mental arithmetic, or being able to study quantum physics, will be significantly easier to some people and more difficult to others. Simply stating that the quantity of effort required by any given person to satisfy a desire is "abnormal" when it is greater than the majority of those who have carried out that desire before, seems an entirely inadequate answer. Absent minded artists concentrating too hard on their latest work to pay attention to numbers, people who are simply physically less fit than their fellows, or indeed anyone who struggles with quantum theory would not seem to be unusually disabled, yet would have different basic effort costs than others undertaking the above activities. Furthermore, this would make assessment of anyone who carries out a desire which the majority do not share, or pioneers a new method of accomplishing something, extremely difficult. Nevertheless, both the definition being formulated here, and principles, such as those of the W.H.O. whose assessment of a disabling condition depends upon assessing its effects upon the amount of effort implicit in carrying out various activities, would seem to indicate that some method of measuring the amount of effort required by any given individual to fulfil a desire or its constituents, against the effort of the majority in a similar situation, is in fact needed in a definition of disability.[75]

One factor which we have thus far not considered with relation to effort, is that of the environment a person is in. It is trivially true that someone living in a country with mains running water, and someone living in a developing country where it is necessary to fetch water from a river must exert vastly different amounts of effort when it comes to fulfilling the desire for a drink. In this case, however, the disparity in amounts of effort is entirely due to differences in the physical environment and has nothing to do with the internal characteristics or attitudes of the people involved. Given the same environmental factors in both cases, i.e. the lack or provision of mains water service, the effort costs would be greatly equalized, which is indeed one of the major arguments of charities and others who seek to change the lives of those in developing countries, by first pointing out the disparity of effort even in carrying out basic tasks, such as drinking or washing, that living in one country as opposed to another causes.

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[75] Towards a Common Language for Functioning, Disability and Health.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Despite disagreement by social theorists however, it does not seem that the disparity of effort costs for any given desire between those categorized as disabled and the rest of the population can be reduced simply to a function of environmental factors, since the characteristic of the disability itself is internal to an individual's self, and not external to it, whereas something like the lack or provision of mains water depends on entirely external factors such as economy, engineering, wealth, etc. Furthermore, when considering the effort of disabled individuals, as noted in the previous section with the train example, even when environmental adaptations are in fact made, the effort costs for a disabled person to perform a given set of activities in fulfilling a desire are not entirely equalized, i.e. it's still going to take more effort to push a wheelchair up a ramp.

It would however be equally incorrect to claim that environmental factors played absolutely no part in altering the effort requirements to fulfil the desires of disabled individuals, in fact Shakespeare, Silvers, MacIntyre and innumerable other commentators working in the social model give many examples of environmental changes which could be made to drastically reduce the difficulties associated with disability.[76,77,78] To take one example, a person with paraplegia may not be able to use conventional transport easily, however given a specially adapted car with an electric lift, wheelchair space, and controls that do not rely upon use of foot pedals, they can drive, and therefore travel with considerable ease. Any theory of "normal" effort then, needs to take into account both the intrinsic qualities of a person and their ability to fulfil a given desire, and the nature of that person's environment as it affects the activities necessary for the fulfilment of his or her desires.

One similar problem is presented in biology. As Griffiths notes, there is an issue in attempting to discuss how well any given species is able to survive within its environment and to what extent the characteristics of that species may be said to give it an advantage.[79] After all, a considerable factor in how well a given species will survive is simply what environment it is in.[80] A fish for instance is ill suited to survive out of water, though better able to survive within it than air breathing creatures.

The writer Canguilhem therefore developed the concept of biological fitness to be used to categorize and quantify the relation between a species' environment and its survival.[81,82,83] According to Canguilhem, a species is "fit" for an environment when it is best

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[76] Colin Barnes, Geoff Mercer, and Tom Shakespeare.

[77] Anita Silvers.

[78] Alasdair MacIntyre.

[79] Kim Sterelny and Paul E. Griffiths, "Chapter 1", *Sex and Death: An Introduction to the Philosophy of Biology*, (University of Chicago, 1999).

[80] Ibid, "Chapter 2".

Also: David J. Buller, *Function Selection and Design*, (University of New York Press, 1999).

[81] Jean Gayon, "The Concepts of Individuality in Canguilhem's Philosophy of Biology", *Journal of the History of Biology,* vol. 31, no. 3, (Autumn 1998), pp 305-325.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

able to survive within it, and an environment is "fit" for a species when that species has the best chance of survival there. Fitness therefore, may be seen to be a relational property, and one which derives from the interaction between a species' characteristics, the nature of its environment, and a measure of how well both of these elements affect a species' ability to survive and reproduce in that environment.

This concept of a relation between environmental factors and an individual's intrinsic nature adding up to a total evaluative measure, is one which it may be possible to apply to human beings, and one which may be able to solve the problem of what a "normal" amount of effort, and a "normal" individual are.

As Urmson notes, in carrying out a single desire, there are a large number of factors leading from intention to fulfilment, and often many subsidiary desires to be fulfilled along the way.[84] As noted previously, we can of course measure the success or failure of a desire by comparing the result to the prior intention, however, between the intention and the eventual fulfilment of the desire is the set of steps taken to carry out that desire, and an expended amount of effort which must be used in carrying it out. This effort may be characterized as the toll of time, physical fatigue, concentration, emotional strain and generalized pressure required to achieve the state of affairs which the original desire aims at bringing about. This may be affected both by factors intrinsic to an individual's nature, and by general environmental factors. Thus, if I desire to travel to a certain destination, I must first determine my route, decide on what preparations I must make for the journey, then concentrate upon my mode of travel, walking, cycling, using the train, etc. How much effort it takes me to travel to said destination will be affected by my own health, ability to concentrate, skills in organization and preparing for the journey and of course my proficiency at walking, driving, catching trains, etc. Then, there is the nature of the journey itself, distance, how difficult the ground is to cover while walking, how much traffic there is while driving, how likely possible obstructions or delays are to occur, etc. If I arrive fully prepared at my destination at my desired time, we can say that my desire was fulfilled. If either the internal or environmental factors change, the amount of effort involved in carrying out the desire will also change, for instance my journey may be made more onerous by an injury such as a broken toe, or by an unexpectedly long detour which requires greater time and trouble on my part to pass.

By applying the acid test established in Section B, i.e., the position of a castaway marooned in a place totally outside social context, it is easy to make a distinction between which factors involved in carrying out my desire to travel are intrinsic to myself, like my

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[82] This is of course slightly altering the debate, since there are theorists who see the crucial factor in species survival not to be simply the whim of environmental change plus characteristics, but how well those characteristics allow the species to specifically adapt to changes in its environment. For our present purposes it is simply necessary to note the interplay of factors in survival, not discuss their importance or relation to adaptation. A detailed analysis of this issue is provided by both Buller and Griffiths.

[83] Kim Sterelny and Paul E. Griffiths.

Also: David J. Buller.

[84] J. Urmson, "Chapter 1", *Aristotle's Ethics,* (Blackwell, 1991).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

ability to walk, and which are part of the environment around me, for instance the amount of traffic on the road (and indeed the conduct and attitude of other road users).

When comparing the amount of effort expended by different individuals to carry out a similar desire, it is worth remembering that, generally speaking, a number of individuals will share a similar environment, thus most of the variation will occur between sets of individual factors, for instance everyone taking my journey will experience the same detour problem, but only I will experience my broken toe, and it is thus within this variation that a standard of normality may be found. A person might then be said to be "normal" in a given environment when they were best able to fulfil their desires within that environment, and "abnormal" when individual factors caused the amount of effort they must expend and desires they must forgo, to increase beyond what is usually achievable within that environment.

This is obviously not a definition of "normality" in the large and monolithic sense used by social theorists, scientists and politicians, such a definition is beyond what I am trying to achieve here (plus it is possible that such an absolute definition of "normality" may not even be plausible), rather it is a test to be used on a case by case basis to establish when, and to what extent, in any given environment a person's desires are restricted biologically, i.e. when a person is disabled relative to that desire within that environment.

Of course, "individual factors" are far more wide ranging than just the biological, and might apply both to those things a castaway would not lose were they taken out of social context, and those factors which an individual is free to alter themselves such as the person with unimpaired hearing who had never been introduced to Mozart mentioned in Section A. There are also factors such as wealth or social class which might vary significantly between individuals sharing the same environment, but are not intrinsic to them, or temporarily internalized factors which may alter the effort costs involved, but are voluntary since an individual may freely give them up at a later date. For instance a drunk person will expend more effort in fulfilling certain desires such as walking but only by virtue of a voluntary state of drunkenness they themselves induced, not because they suffer from an internal state that causes the activities necessary to fulfil those desires to increase in effort. Obviously all these factors will cause variation between individuals, but it is the difference in effort involved between individuals whose internal characteristics are involuntarily different, that is the main concern here.

It is entirely possible that given other forms of acid test than the castaway, and other ways of isolating individual factors for comparison, other forms of abnormality, i.e. other sets of individual factors which cause a decrease in effort and lack of desire fulfilment among definable groups of individuals sharing the same environment, what are in effect other senses in which individuals may be normal or abnormal, may be discovered.[85] However, here the

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[85] One highly similar example of such a test, though one far less specific than the castaway test and intended more to establish social justice than normality, is John Rawls' idea of the Vale of Ignorance[85a]. This places the theorist outside society, but rather than comparing them to others, asks the theorist to formulate a system of justice based on the idea that they will be reincarnated as any member of society with any given set of circumstances and thus forces the theorist to consider everyone's good as equal to their own. It is possible that a modification of this idea, by asking the theorist to consider the likelihood of certain individual, involuntary, or environmental factors in their next incarnation, and how such likelihoods should affect others, that a more wide ranging theory of normality may be created which can then be used to establish a standard for comparing various forms of individual circumstances.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

concern is with disability, i.e. with the variations in effort caused by individuals' unalterable internal factors as picked out by the castaway test, thus, a prince and a pauper may take very different amounts of effort in getting what they want, however, according to the castaway test neither is disabled because neither wealth nor poverty would remain once society was removed from the equation, so that the standard of "abnormality" does not apply. Were we to apply another test of comparison, possibly by comparing the amounts of money each possesses independently of other factors, then indeed we might judge that one is poor and the other rich, and that this is an inequality.

Since the achievement of desires and expenditure of effort is on a sliding scale, we may also here reintroduce a notion of majority, more specifically the notion of how much effort or what desires the majority of individuals in the same environment fulfil.
As it is based upon the isolation of involuntary individual factors via the castaway acid test and how those factors relate to groups of individuals within the same environment, such an idea of majority is able to solve many of the issues raised with gross majority categorization earlier. For instance, since the individual factors identified by the castaway test must be involuntary, a distracted artist (who could freely concentrate on numbers if they desired), no longer is a possible candidate to be classified as "abnormal" when set against the standard of disability, as the artist's distraction is a state she/he induced voluntarily for the completion of his/her art work and could relinquish if she/he wished.

Also, as it concerns the variation between individuals in a similar environment and the ability to carry out desires, "normal" depression or fear is easily established, as it is simply necessary to compare the extent to which the desires and freedoms of the majority are negatively affected by such feelings as compared to someone with clinical depression. So, whereas a statistically average person who felt "normally" depressed would still be able to get out of bed in the morning, a person disabled by depression would not.

On this view, the problem of categorizing M.E. as a disabling condition noted in Section A would not have arisen, since it would be an internal involuntary state of a person which causes him or her such a level of fatigue that the amount of effort required to fulfil desires is far greater than the majority of people in the same environment, i.e. citizens of the same country.

It is also worth noting that recognizing what amount of effort and what variation in that amount of effort a majority might use to fulfil a desire allows the limits of certain negative internal conditions to be defined. One of the best examples of this occurs in (of all places) a book I recall from my childhood, *Little Miss Shy* by Roger Hargreaves, a book in the "Mistermen" series, which explores characters relative to one defining characteristic, e.g. Mr. Happy, Little Miss Trouble or indeed Little Miss Shy.[86]

Little Miss Shy is invited to a party, but being obviously shy she greatly fears going despite having a desire to. This desire causes her to experience considerable trepidation and

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[85a]John Rawls, *A Theory of Justice*, (Belknap 1971)
[86]Roger Hargreaves, *Little Miss Shy,* (first published 1981, republished Egmont, 2014).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

repeatedly change her mind about whether or not to go. Eventually, she decides against going, however, just as she begins regretting her decision, the extravert and fun loving Mr. Funny arrives and explains that he's come to fetch her, whereupon she attends the party and enjoys herself.

Though a childish example, the above story (especially considering it as a parable for dealing with shyness) illustrates an example of how a certain level of shyness may be appropriately dealt with and a desire fulfilled despite the individual's possession of an internal characteristic which causes problems in fulfilling that desire. More broadly we could say that Mr. Funny, as a feature of Little Miss Shy's environment rendered her fit to fulfil a desire despite a certain amount of a given negative state, i.e. shyness.

If, however, Little Miss Shy was so overcome by fear she locked the door when Mr. Funny arrived, or went to the party, stayed for the first five minutes and ran out in terror, she would be in a position in which the level of her shyness had escalated beyond the point where the environmental factors which related to it were able to alleviate its negative effect. At such a point, the level of shyness could be said to be approaching a state of disability.

A similar argument regarding mental illness is made by Wakefield, that it exists relative to cultural norms, however this argument only covers a person's mental state, and also places the level of cultural beliefs and practices in what seems to me a dangerously dictatorial position with respect to an individual's desires, which is why I believe desire satisfaction and the comparison of individual abilities to attain it versus the environmental factors that individual shares with those around them is a far more reliable method to identify the normal and abnormal, and indeed the disabled, as opposed to simply what a given set of cultural practices say.[87]

Having now, finally, established a standard of comparison by which both the effort expended by individuals and groups of people with medical conditions may be specifically examined and categorized as different from that of the majority in the same environment, we can finally formulate a concrete definition of disability in terms of its effects upon quality of life which may be then applied to other issues such as accessibility, social prejudice and the matter of human assistance.

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[87] J. Wakefield.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section F: Definition

We have examined the nature of the term disability, how it differs from inability and yet carries both purposive and judgemental overtones. We then examined how this term has been applied medically to certain individuals and attempts by the medical model to define it, and how such attempts fell short due to subjectivity, reliance on simple majority judgements and inability to state in what ways precisely disability is a form of harm, as opposed to the irreducible harm of pain.

We then turned our attention to the factors involved in possession of a disabling condition, and how the social model attempts to ascribe all these factors to society. This however, as we saw, is also not a tenable approach due to individual differences between disabilities and the fact that not all the negative effects of disabilities can be traced to social causes, so we attempted to establish the castaway acid test by which those elements of a disabling condition could be isolated from social or other environmental factors.

We then turned to the effects of a disabling condition and why such a condition is bad for the individual who possesses it, how it impacts upon the desires of a person, both in terms of directly frustrating the fulfilment of desires, and by increasing the amount of effort necessary to carry out desires, thus having an overall detrimental effect upon a person's well-being and their ability to live aneudaimon life.

Finally, we attempted to reintroduce a standard of normality as compared to disability, and found how, by focusing on an individual's relation to her or his environment, and how those intrinsic, involuntary characteristics of an individual isolated by the castaway acid test may be compared to the majority in terms of fulfilling desires and effort, a case by case test can be used to formulate a method to distinguish a "disabling" condition, and the extent to which that condition affects an individual.

Therefore, we may propose the following definition:

A disability is any intrinsic state of an individual's physical or psychological nature which that individual may not freely relinquish, and that individual would still possess even outside her or his current social context, which causes that individual to suffer a diminution of his or her ability to fulfil desires, a lessening in the availability and number of desires which that individual may ultimately fulfil, and a greater amount of effort in the fulfilment of the desires he or she does possess, as compared to the desire fulfilment and effort taken by other individuals sharing his or her environment who do not share that internal, involuntary state.

Of course, this definition is extremely subjective and intended primarily as a test to be applied in different situations and circumstances, rather than a purely static categorization. If an examination of the existing models shows anything, it is that disability is not a scientific term that applies to just one category of objects, or a term of identity that applies to one set of human individuals. It is a state of being, an interaction between a person's basic self and the environment. It is a negative preclusion of a person's desires, an involuntary state, but one which the vast majority of humans will, to some extent, temporarily or permanently experience throughout their lives. It is for this reason that the above definition is intentionally

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

individualistic and flexible; a flexibility which it is hoped will allow a far more realistic and reasonable consideration of the freedom, desires and lives of anyone who experiences a disabling condition which, as I have indicated, will be almost everybody at some time.

In making disability both universal and practically dynamic, I hope to open the debate to allow far more realistic and ethical treatment of those with disabilities, not as medical abnormalities or as a "special interest group" but simply as individuals who, whether as members of a society, patients at a hospital, or just people we ourselves encounter throughout life, deserve as much consideration of their freedom and well-being as anyone else.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Chapter 2: Persons with unconscious disabilities

Introduction

The definition offered in the previous chapter, while hopefully broad enough to take into account most forms of physical and psychological disability, may however present problems when applied to one particular group of people commonly recognized as disabled, those whose cognitive faculties or understanding of the world is such that they themselves do not recognize that they are disabled, i.e. that their achievement of desires, or freedom to access certain desires, is affected by their physical or mental state.

One of the primary examples of such a group is the group now represented in governmental legislation as learning disabled. Though some with mild learning disabilities may indeed recognize that they are at least different from others around them, those with severe learning disabilities, categorized as P.M.L.D., or profoundly multiply learning disabled will generally not be able to do so, as their intellectual abilities will be far less than those of an average adult and so they do not recognize the fact of their lessened capacities for achieving well-being, as compared to those around them. This distinction covers both those with severe learning disabilities such as autism, as well as those who have suffered forms of brain damage.

I feel that any definition of disability must be able to encompass those in this position just as much as those with usually understood disabling conditions such as blindness or paraplegia. After all, profound learning disabilities are always treated under the umbrella of "disability" in our common understanding, and it is undeniably true that such conditions are involuntary, integral to the self and have profound effects upon the lives of those who have them. Yet those with cognitive disabilities, particularly those who are unconscious of their status as disabled, are a group whose interests, experiences and indeed even identity has been very much underrepresented in most of the discourse on disability, despite the fact that, unlike other groups categorised as disabled, those with cognitive impairments are by definition unable to represent themselves or recognize their own identity, indeed this asymmetrical relation to society seems to suggest that the basic assumption of the social model itself is inadequate to this task.

I have some personal experience in this area since my sister is diagnosed with congenital myotonic dystrophy and cerebral palsy, and so is categorized as P.M.L.D. by governmental standards, and is thus part of the group mentioned, since her cognitive understanding will in no way be such that she recognizes her own disability. I hope therefore, through reflection upon some of my personal experience of life with her, and with the establishment of some conceptual tools, the definition offered in the first chapter will be able to work out a framework for discussing the desires, experience and quality of life of people within this group, something which the existing discourse on disability has failed to do, and something which has extremely wide-ranging applications outside the field of academia in

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

education, social care and daily life, matters very much affected by how those with any form of disability are perceived and treated by the rest of society.

Thus, in Section A, I will first review what precisely is meant by "unconscious disability" and how the existing theoretical research has not taken this group into account, and yet it is the unconsciously disabled who, being under-represented and generally unheard in much disability discourse, as well as possessing lives whose experience is heavily based around interactions with others (often medical professionals or carers), have most to gain from proper consideration and representation of their interests, and most to lose without it.

In Section B I will examine the lives and desires of the unconsciously disabled and their status as agents and bearers of desire, what information is lacking in their lives and ability to make choices about desires, and to what extent they may be said to be disabled.

In Section C I will compare those with profound learning disabilities to a very similar group, children, and thus hopefully come to a more clear understanding of the status of their lives and experiences.

Finally, in Section D I will compare these issues to my earlier definition, taking into account issues such as effort, in an attempt to establish methods of considering the lives and experiences of people in this underrepresented category, and how this might affect the definition previously offered in Chapter 1.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section A: Discourse on unconscious disability

The sociologist and disability advocate Tanya Titchkosky believes that a correct application of disability studies, a newly emerging speciality discipline followed by theoreticians working in the social model, must have its roots as much in notions of the phenomenology of disability, as in society's treatment of those categorized as disabled.[88,89] Working as she does from a sociological background, her focus is on understanding the experiences of different groups of people socially categorized as disabled, and how they interact with general views of the world and the objects it contains. So for instance, what for a person with normal mobility might be an attractive ornamental piece of ironwork on an artistically created (and thus unusually shaped) set of steps, will prove for a paraplegic an insurmountable obstacle to entering a building.[90] Thus, according to Titchkosky, much of the world is socially created by those categorized as "able bodied" with their specific values and capacities in mind, for example a desire for ornamentation over easy wheelchair access. This, Titchkosky contends, leaves no room for the experiences of lives lead by those with impairments.

This is a perfect and structured statement of the social model's most basic tenet, dividing the experiences of those with disabilities from those without them, because, according to the social model, the intrinsic categorization of both groups of people denotes a distinctly different form of experiencing the world, a majority and minority world view held in opposition to one another. It is therefore intrinsic to this model that those categorized as disabled know that they are disabled and understand the relation of the world's objects to them, that people with paraplegia recognize the intrinsic difference between their own mode of locomotion (usually a wheelchair), and the "normal" method of walking, or that blind people recognize that they lack visual information about the world around them, and thus are excluded from many aspects of society, everything from signs and print to non-verbal communication.

There are however, those who are categorized as disabled by definitions, such as that of the World Health Organisation, who cannot be said to fulfil this requirement, since their

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[88] Tanya Titchkosky, "Chapter 8", *Disability, Self, and Society,* (University of Toronto, 2003).

[89] This view is also expressed by various other exponents of the social model who claim that the experiences of different groups of disabled people are categorically different from what are often called "the normals", and that it is society's inability to "recognize different experiences" in which lies the real identifying characteristic of disability. Titchkosky however, goes slightly further in her tying of personal experiences of disability to varying ways of "being in the world" rather than tying the social origin of disability more explicitly to something such as a dominant concept of the body or a simple prejudice. I will examine the nature of social relations and attitudes more specifically in Chapter 4, however for purposes of our present discussion it is merely necessary to note this often emphasized link between specifically, socially created ways of comprehending and being in the world, and disability.

[90] Tanya Titchkosky, "Chapter 5".

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

perceptions of the world, its objects and their relations to it, will simply not fall into this pattern of group experience, particularly those with extremely severe forms of mental illness, autism, and more generally those categorized as P.M.L.D., or profoundly multiply learning disabled.[91]

Whereas the person with paraplegia would recognize the existence of the steps from Titchkosky's example, if they fell into this category, i.e. possessed some sort of cognitive impairment in addition to their paraplegia, they may recognize the steps only as a break from the point that a parent or carer pushes their wheelchair into the building, or even not recognize them at all as an object which has any sort of effect on the course of their life or experience.[92] Indeed, for some people who are extremely severely cognitively disabled (those categorized as P.M.L.D.), the inability to recognize steps is itself a profoundly dangerous situation and one requiring input from others such as parents, teachers or carers, especially when the person themselves has other impairments that affect their mobility.

There are of course others who, despite possessing "normal" intellectual capacities are still "unconscious" of the significance of certain social objects or situations with respect to themselves, i.e. their disability. Tanya Titchkosky herself details her life lived with dyslexia, and the effect this had through school and university when she believed her difficulty with writing was her own failing through lack of practice or clumsiness, that it was in fact a voluntary, rather than involuntary condition and one which was the result of some character flaw that she herself could avoid such as laziness or wilful misunderstanding.[93]Similar accounts of self-destructive comparison to others and a belief that involuntary effects of a disability were in fact failings on the part of the individual have been reported by sufferers of many conditions such as M.E., indeed it was this fact which caused the diagnosis and classification of M.E. in the first place as a distinct condition in its own right, as previously noted.

The case however of someone experiencing a condition they may not be aware of which is impacting their ability to fulfil desires, seems to be a different state of affairs from the case of someone with a more general cognitive impairment. Titchkosky was able to compare her own levels of effort, time and trouble taken with writing, comprehending information such as directions on a map, and similar tasks to those in approximately the same position as herself, effectively to establish an idea of what should be "normal" quantities of

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[91] Towards a Common Language for Functioning, Disability and Health.

[92] Of course, the mobility difficulties presented by obstacles to the movement of a learning disabled person who also has paraplegia will have an impact on the lives of those around them such as family members or carers, and it is for this reason that government benefits and services exist. However, it would be utterly incorrect to confuse the experiences of a disabled person and his or her assistant or carer in any task, even though they may be closely linked in the fulfilment of the desires of the disabled person. I will examine this relation when considering the question of human assistance more generally in the next chapter.

[93] Tanya Titchkosky, "Chapter 1".

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

effort or efficacy in that given situation which she was then able to apply to her own circumstances. In failing to recognize that her amount of effort was equal, or even greater than, the normal amount a person expended in such tasks, she attributed her failing in them to her own character inequities. This indeed is common with people possessing a disability they are unaware of, whether this is a person in the first stages of sight loss straining their eyes at a far off object, or a person experiencing mental illness finding themselves more seriously affected by their emotional or mental state to a point where it significantly impacts upon the rest of their life.[94]

As many commentators on the social model have noted, it is this tyrannical standard of normalcy which often causes a large amount of suffering for disabled individuals. This situation though, is still in no way analogous to that of a person with a condition such as P.M.L.D., since the person experiencing the disability is merely unaware of some facts about themselves. Upon being made aware of these facts, they are able to recognize their significance and integrate them into the rest of life, for instance by finding strategies whereby they are able to reduce the amount of effort and time required in engaging with activities or situations directly affected by their disability, thus while being made aware of these facts does not eliminate the disability itself, it does nevertheless allow the individual more control and understanding of their life, and also end their adherence to the overbearing standard of normality which may have caused considerable problems for them on its own, (I will return to this topic in Chapter 4 when considering how people with disabilities relate to others).

The form of unconscious disability however, which I am attempting to address here, is that possessed by a group of people whose disability itself precludes them from understanding that it actually exists. People who cannot perform the effort based assessments mentioned above, or understand that their condition is involuntary, or even in severe cases understand that the effort or suffering they need to undergo to achieve a goal or participate in certain aspects of life can be related to a similar amount of effort in other people. It is the difference between a person being temporarily unaware of a fact about themselves that they may at any time be made aware of, for instance high blood pressure, and a person told a fact about themselves which is so profoundly alien and beyond their understanding that it can play

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[94] This comparison of a "normal" effect upon a person's life is used in psychiatry to establish whether or not a condition such as depression is "chronic", i.e. at the level where it may be considered to be a disability. There is a considerable and long running debate concerning whether the categorization of those with mental illness as in fact "ill" is simply an imposition of society's view of reality and what a person's beliefs should be upon a minority, but that would seem to be a much separated issue from the problem of disability, since disability concerns (as stated in the previous chapter), an involuntary state which interferes with the desires of a person, not a voluntary state which simply conflicts with society's views. Indeed, conversations I have had with a number of people with mental illnesses such as depression and schizophrenia seem to indicate a case far more similar to Titchkosky's account of dyslexia, where their efforts at fulfilling desires differed from those around them, so it seems reasonable to assume that, at least for some of those with mental illness, the state is involuntary and they do indeed count as disabled, albeit that there may also be cases of those diagnosed as mentally ill who do not.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

no part in their self-assessment or how they conduct their life, and no amount of explanation will change this. It would be like attempting to convince a Neanderthal that disease was caused by microscopic organisms invisible to the naked eye and to alter their lifestyle accordingly, though even in this case it is conceivable, given enough education to create a shared field of reference, that the Neanderthal might grasp the concept, whereas in extreme cases of unconscious disability there would be no possibility of this at all.

I also feel that while the topic of what might be called the temporarily unaware disabled has received a large amount of theoretical attention, the same is in no way true of those who are absolutely unconscious of their disability. As Chappell notes, many social theorists have simply ignored those whose disability causes their intellect to be in such a state that not only do they not recognize they are disabled, but they do not recognize even basic objects in the same fashion as "normal" people.[95,96]

Sara Goering indeed categorically refuses to even engage with those with unconscious disabilities, on the basis that the "purpose" of the social model of disability is purely that of group advocacy, and though she acknowledges the importance of "understanding" those who cannot speak for themselves or form distinct social groups, she states that, since the purpose of the social model is group identity, such people directly fall outside its purview.[97]

Swain and French on the other hand do suggest that the social model may be able to come to terms with this issue by engaging in dialogue with people with such conditions, and thus gain an understanding of the "social experience" of learning-disabled people.[98] However, though Swain and French both do present some examples of interviews with

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[95] Anne Louise Chappell.

[96] Chappell believes that this lack of accounting by the social model is more a matter of its focus upon the body as a socially created object, and the disparity between "the disabled body" and "the normal body" rather than elements such as the intellect. While this explanation would also account for the reason that, though they are often medically counted as disabilities, forms of mental illness are not usually discussed in the same light, this form of analysis goes beyond what I am trying to achieve here, since I am trying to establish a newly constructed definition which takes into account a lack in previous discussion, rather than simply demonstrate why such a lack may have occurred in the first place, though I will return to the topic of how social perceptions of disabled individuals relate to my desire based definition in Chapter 4.

[97] Sara Goering, "'You say you're happy, but …': Contested quality of life judgements in bioethics and disability studies', *Journal of Bioethical Inquiry*, vol.5, no. 3, (2008), pp.125-136.

[98] John Swain, Sally French and Colin Cameron.

Also: K. Keema, "Chapter 2", *Inclusion or Segregation.*

Also: John Swain, "What's So Good About Independence?", *Controversial Issues in a Disabling Society,* ed. John Swain, Sally French and Colin Cameron , (Buckingham: Open University Press, 2003), pp 76-86.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

people of mild learning disability, this still does not take into account the experiences of those with more profound conditions who categorically do not understand that they possess any form of disability, yet whose lives and experience may be most profoundly affected by their physical and psychological state. So, as Swain notes, while it is possible for Peter, a person with Down's Syndrome experiencing mild learning disability, to utilize and understand the uses of governmental direct payments to advantage in his life, this option would not be open to those with more severe learning disabilities, since unlike Peter, they have far more difficulty in actually articulating and structuring their experiences and desires and what choices they wish throughout life, despite the fact that this very lack and reliance upon others would make a system, such as direct payments and its administration to their benefit, of even greater significance. It may also be the case that even if a person, for instance someone with autism, understands that they are "different" from others, they do not attach any significance to this fact beyond its mere existence, or are able to actively consider the significance of why they are different at all.

Of course, though I have attempted to draw a distinction between unaware and unconsciously disabled for the purpose of this discussion, the quantity of understanding is largely proportional, and therefore strict categorization here is impossible. For example, a child with learning disabilities and paraplegia may be quite aware that they are unable to play football like other children, but not be able to understand the reason why. It does however, seem to be the case that in theoretical terms, while some commentators like Swain and Chappell have attempted to extend the social model of disability to those with a limited understanding, very little effort has been made to encompass those with none at all. Yet, since they do not have the ability to share their "social experience", and because they are often treated merely as the objects of the perceptions of others and so even more seriously subject to the vagaries of their environment, the more unconscious of their disability a person is it seems the more they are in need of theoretical attention and representation than many other more vocal groups of those who are usually recognized as "the disabled".

This can be seen in the formulation of the Warnock Report and the original governmental policy on the education of profoundly disabled children in 1973.[99] As Mary Warnock explains, before the writing of this report, children with certain levels of disability were held to be uneducable, since they were not capable of learning to read, write, etc. They could, and did, receive basic physical care, but the idea of actually creating any sort of specifically designed, education programmes for them, or even that their education could be of any value at all was completely unknown. Needless to say, this was definitely in line with the thinking of the time which was dominated by the "disability as illness" schema of the medical model, and saw those with profound learning disabilities as simply "long term care patients," as Newell observes.[100]

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[99] Mary Warnock, "Chapter 3", *An Intelligent Person's Guide to Ethics,* (Gerald Duckworth, 1998).

[100] Christopher Newell.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Mary Warnock however, questioned what exactly the purpose of education was. Rather than simply being understood as achieving the ability to write, perform arithmetic, etc., she proposed that the purpose of education was to achieve a certain level of control over a person's environment, and thus make it easier for a person to enact the fulfilment of his or her desires. Thus, for a profoundly disabled child to learn how to use a switch communicator to choose between two flavours of ice cream was, according to Mary Warnock, a reasonable goal of education.[101],[102]

Yet, whether a profoundly learning disabled child received this form of education, or was encouraged to learn to articulate such choices was simply a matter of governmental and bureaucratic policy, and was far more a product of the sympathetic or pragmatic thinking of the time than any attempt to consider children's actual interests. This is why, even today, the type and mode of education received by learning disabled children is often related only to the attitude of the school they happen to attend, and not related to any larger consideration of what educational needs will be of most benefit to them personally. So, following Mary Warnock's reasoning, it does seem that profoundly disabled people can be recognized as having desires, and that they stand in a relation to their environment by which those desires may or may not be fulfilled, albeit that the objects of those desires may not be similar objects of desire to those recognized by other members of society, and that the attainment of those desires may involve a vastly different process of intermediate steps.

This similarity in form related to desires and their fulfilment needs to be emphasized, since a very worrying tendency exists in certain commentators to see unconsciously disabled people just as tools of moral example, or means to a moral end, rather than ends in themselves. Macintyre for instance, states that profoundly disabled children should be valued because they give those around them the chance to exemplify and practice moral virtues, and opportunities to develop unusual relationships.[103] This may be true to an extent, since those who come into contact with the unconsciously disabled may indeed perfect some virtues, however it says little about the status of the unconsciously disabled themselves. It tells us nothing about how the experiences of unconsciously disabled people and their interactions

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[101] Some commentators such as Michael Smith have heavily questioned Mary Warnock's motives, indeed in Smith's opinion, the Warnock report was more concerned with transferring responsibility for profoundly disabled children from the health service to the education service. I, however, am more concerned with Mary Warnock's philosophical, rather than political motives for the formulation of her report, which would seem to be based upon improving the quality of life for those with an unconscious disability, and the idea that the government's responsibilities for providing education apply just as equally to cognitively impaired children. I personally find Smith's attribution of ulterior and indeed quite self-centred motives to Mary Warnock, which differ markedly from the ones she expresses herself, less than convincing, but such a debate is best left to political historians.

[102] Michael Smith, "Does the Evaluative Supervene on the Natural?", *Well-being and Morality: Essays in Honour of James Griffin*, ed. Roger Crisp and Brad Hooker, (Oxford: Clarenden Press, 2000), pp 91-114.

[103] Alasdair MacIntyre, "Chapter 9".

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

with the environment should be considered and valued, the way the fulfilment and happiness of other humans is considered as a valuable end in and of itself.

A far cruder, and more worrying expression of this view, is seeing profound disability as an expression of sentimentality with a vaguely moral bent. J. David Smith, in his book *In Search of Better Angels* discusses many cases of "lessons he's learnt" from working as a teacher with profoundly disabled children, and indeed concludes that the main benefit of such children is simply the ability to show, "A glimpse into our own unselfish moral nature," and wishes that more people would undertake working with profoundly disabled children in order that society receive this benefit, a view which is often exemplified by the media or even organizations such as charities supposedly working in the interests of profoundly disabled children.[104] This view however, though many have found it attractive, hides a form of thinking which on closer inspection seems extremely repellent, since it reduces the status of the unconsciously disabled to essentially that of a doll or a pot plant, i.e. an object upon which we can practice being moral in order that we may show moral behaviour towards "real humans" later on, but an object whose actual desires and experience do not in themselves matter half as much as they would were the person "normal". This is a perfect case of treating such people only as means to another purpose, albeit the highly laudable purpose of practicing moral behaviour and developing personal virtues, rather than as an end in themselves with desires that actually have intrinsic value to them.

But, as Mary Warnock demonstrates, the majority of those in the P.M.L.D. category do possess desires, do interact with the environment and do plainly have a life with its own structure and experience which can benefit from the possession of the ability to make choices over what those experiences involve.

Yet, at the same time, it cannot be denied that many of the concerns which cover other groups classified as disabled may simply not be applicable to those in the P.M.L.D category. There would be little sense, for instance, in attempting to make an adjustment to the steps in Titchkosky's example to allow profoundly learning disabled people access to the building, since they may not have the ability to recognize that freedom of this access is of any benefit to them, and indeed, depending upon the function of the building in question, it may not be, for example if the building were a polling station for voting in an election.

The major problem in dealing with the unconsciously disabled, and P.M.L.D in particular, is that nobody has so far asked the question of exactly how those with profound disabilities may actually be said to be "disabled", and in what ways their lives are limited, and how we should think of such lives,(other than as a moral example). This question is obviously difficult, since unlike those with more understandable sensory or motor impairments, or those with psychological conditions such as depression which cause

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[104] J. David Smith, *In Search of Better Angels: Stories of Disability in the Human Family,* (Corwin, 2003).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

increased effort, the unconsciously disabled may not be in a position to understand that they "are" disabled, as noted previously.

Thus, it will be necessary to turn to the nature of desires, and exactly what types of desire the lives of those who possess an unconscious disability involve, and in what ways these desires might be frustrated to establish the nature of their disability.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section B: The quality of life and desires of those with unconscious disability

The first and most major issue in discussing those with unconscious disabilities is that perhaps, even more than any other commonly recognized group of humans, the actual nature of their lives and capacities for well-being can vary extremely. In a discussion with David Stewart, O.B.E., head teacher of Shepherd School for severely learning disabled children (the school my sister attended), he revealed that though many researchers asked to perform research with his pupils, asking for people with specific conditions such as Down's Syndrome or children who had a basic understanding of some given thing such as numeracy, it was often extremely difficult to separate children into one category or another, since the abilities and understanding of the children showed a huge degree of variation. Some were or were not able to walk, some were or were not able to speak, some recognized people, some did not, etc. This is the reason I have simply classified this group as "unconsciously disabled" since this seems to exemplify the theoretical problem provided by those who are medically and socially classified as having a disability, but are not able to recognize this fact or attribute such a distinction to themselves, yet unlike any medical definition of capacity or any arbitrary distinction such as I.Q. scores, it is able to encompass the whole of this group simply by virtue of the faculty of self-perception relative to others.

As Mary Warnock noted, David Stewart did confirm that desires, relationships and general quality of life were still a question of importance to the vast majority of those categorized as P.M.L.D., so simply classifying them, as Warnock's opponents did, as "vegetables" which just grow and require care but have no ability to have desires, or participate or engage in experience, is purely incorrect.[105] This is also something I've noticed in life with my sister: her capacities to enjoy certain things, and not others, and her capacity to interact with people and form relationships, even if not based on spoken interactions since she cannot speak more than four or five words.

At the same time however, it is true that the desires of many experiencing learning disabilities and in particular those who are not conscious of having a disability will differ markedly from the desires of the majority of people, and may preclude things which are commonly thought of as of critical importance. For instance, as noted previously, while a wheelchair accessible entrance to a building is a desirable thing for a person with paraplegia, since without it they will not be free to enter that building, when viewed from the perspective of a person with any form of unconscious disability this desire for freedom of access does not directly apply since by the very fact of being unconscious of their disability, the person has no ability to recognize that they are missing something important by not possessing that freedom.

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[105] Mary Warnock.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

This case is even less clear than that of the oppressed people offered in the previous chapter. While an oppressed people who have never known political freedom may, in some possible world with different circumstances, desire and benefit from such freedom, there is categorically no possibility that a person with an unconscious disability would recognize this lack in freedom and still be unconscious of their disability. Of course, someone with learning disabilities may wish to participate in whatever activity is going on inside an inaccessible building, such as attending a play, or watching a film in a cinema, however the simple factor of being able to enter independently in and of itself does not seem to have the same significance to them, since a desire to "go to a show" is a separate one from the desire to enter a theatre whenever desired.

Furthermore, on the subject of freedom, it indeed may be the case that some desires of people with learning disabilities are, by their very nature, those which we would wish to actually frustrate simply on the basic, common sense level of living a life free of pain. Say for instance, the desire to put a hand into a fire. Curtailing a person's freedom in respect to this desire would seem to be quite reasonable even though restrictions on people's freedom are generally problematic to justify. At the same time though, despite the fact that freedom to plan life goals or activities might be problematic for many unconsciously disabled people, it is clear that possessing a given freedom to do something can in itself be pleasurable even in cases where such a form of freedom exists only to give that pleasure. I, for instance, remember the first time my sister was able to play with an electric wheelchair propelled by joy stick, as opposed to simply being pushed. She definitely enjoyed this experience incredibly, and yet there was no express purpose to it other than its own enjoyment, since it was not possible for my sister to understand or safely use an electric wheelchair to propel herself between desired destinations like a paraplegic person with "normal" intellect. This does seem a form of freedom, a freedom of movement, but a freedom of movement existing simply for the purpose of pleasure, even if it will not, due to the intellectual restrictions of the profoundly learning disabled person, be of use for any further, second order purpose such as travel or mobility.

Several commentators working in desire theory, such as Sobel and Griffin, appeal to the idea of informed or second order desires as a method of grading and deciding upon the importance of desires, in order to suggest which should be satisfied to produce the best quality of life.[106] According to this position, some form of intellectual understanding is used to deliberate upon desires and decide ultimately which should be satisfied. Thus, to a person of normal intellect, even if they were to feel the desire to put a hand into a fire, previously acquired knowledge of the effects of fire would instantly persuade them that such a desire was not in their best interest.

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[106]D. Sobel.

Also: J. Griffin, "Chapter 2".

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

According to this informed desire schema, secondary, experiential desires such as the desire for a particular food are in many ways less important, and less crucial, indeed many who have written on desire theory maintain the position, first elaborated by writers such as Hume and Jeremy Bentham, that intellectual desires, or desires which relate to entire lifestyle choice and by which an entire life may be guided, are in some way more worthy and more admirable to cultivate than other forms of desire, expressed by Jeremy Bentham in his remark that he'd rather be Socrates unsatisfied than a pig satisfied, since even unfulfilled intellectual desires were better than fulfilled physical ones.

Thus, with this view in mind, the lives of those with intellectual disabilities are in many ways less easily quantified, simply because the "informed" desires are in many senses less prevalent because (depending upon the severity of the intellectual impairment) perceptions of the future, or ability to enjoy intellectual pleasures are simply not present, and the more immediate desires for food or instant perception of currently pleasing objects are more evident, such as a desire to continue listening to music or watching a children's TV programme. It is for this reason that Peter Singer characterizes people of reduced consciousness as of less moral value, though it is also noteworthy that when his own mother fell into such a state due to age, he did not maintain this consideration (showing clearly that he was far from practical in his philosophy's actual impact on his life).[107]

Yet, thinking of those (as Singer plainly did) with intellectual disability merely as creatures of whim with no ability to enjoy or experience anything beyond immediate sensory satisfaction does not seem in any sense accurate, indeed it is dangerously close to the pejorative "Vegetables" employed by Warnock's opponents.

Mary Warnock recognized that education could provide profoundly disabled children with the ability to make choices and have degrees of control over their lives, and that in possessing these controls, profoundly disabled children could indeed develop and perfect their own preferences and desires, and through experience, albeit experience often on a very singular level, acquire a set of second order desires specific to them and some of the needed tools they could use to enact those desires. In the respect of acquiring "informed" experiential desires, the structure at least of the desire schema of profoundly disabled people is little different to anyone else's. My sister definitely has her own preferences for music, food, company and other forms of experience, preferences which also make her very distinctly "a person" (despite Singer's contention).

While the fact of more complex second order desires however, may provide something structurally similar in the lives of P.M.L.D. individuals to those of other humans, it is nevertheless also true that their lives will be vastly different.

If one flavour of ice cream is desired and another is not, due to previous experience, this desire may be said to be "informed" to the extent that past experience and information

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[107] Peter Singer, *Practical Ethics,* (Cambridge University Press, 2011).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

are involved in its choice, a choice which can only be made with reference to this prior experience, even if the basic nature of deciding between choices of this type would not usually be held by commentators as an example of an informed desire. However, it is also true that other, more complex forms of informed desires, such as the desire to enact a full scale life plan, or endure temporary discomfort for a future benefit, are far less evident. While my sister certainly possesses extremely strong desires for certain experiences over others, even if this comprises, for instance, preference for one sort of music over another. While making these choices via her past experience she is certainly quite as informed as anyone else making a similar choice, this does not stop her disliking necessary procedures such as breathing with oxygen.

Both according to statements by David Stewart, and by experiences such as those of David Smith, it is in no way true that the only desires experienced by many people with learning disabilities are merely physical ones, indeed relationships and interpersonal feelings, towards parents, family members and carers, and towards peers, are very much in evidence, as noted previously.[108] Yet this point is often also made in connection with informed desire theory as well. As Griffin notes, "informed" desires may be as much a matter of the passions and emotions as of purely intellectual thought.[109] It is, I believe, partially this understanding of emotional connections which fuels some of the sentimentality of writers such as David Smith, who find the existence of emotional connection in the lives of cognitively disabled people so surprising. It seems such sentimental reactions as Smith's automatically assume some sort of proportional relationship between ability to experience emotional attachments and intelligence, and then are surprised when this belief is contradicted.

Nevertheless, it is also completely true that many of those with reduced intellectual capacities are often unable to distinguish between past and future events and are thus unequipped to make plans of action, or feel emotional anticipation, which go beyond the next few moments. It would be impossible for instance, to ask someone in this group to distinguish between two sets of future circumstances set ahead in time, such as the decision between two holiday destinations or two schools. Thus they are clearly not able to make a great many informed or considered decisions about their own well-being or the fulfilment of their desires over time. Such decisions are usually left to those around them, those who, it is hoped, are sensitive to the interests and past experiences of the people in question, and are thus able to distinguish the difference between a number of temporally more distant future possibilities which the profoundly learning disabled are unable to. For instance, my sister greatly loves theatrical performances and shows such as pantomimes. It is however, not possible for her to read a show's description from advertised material, or even for this description to be comprehensible to her if the material were read to her or accessed in a different format as a visually impaired person would. It is therefore up to my parents to

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[108] David Smith.

[109] J. Griffin.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

observe what shows are on at the theatre, and decide based upon their knowledge of my sister's own preferences what she would, or would not be interested in seeing.

It does seem therefore, that people with intellectual disabilities can be said, to an extent, to experience a lack; a lack in the capacity to formulate informed desires or perceive relevant information which would contribute to their formulation. This lack may be somewhat similar in fact to that of those with sight impairments' experience in lacking the capacity to take in visual information and participate in desires that require this information. However, unlike sensory impairments, the intellectually impaired person is not free to wonder what possessing the capacity for informed desires actually is, or even perceive the capacity they do not possess, nor are they able to access the effects of this capacity in an alternative form. Yet, as noted in the previous chapter, this might even be considered a blessing in some circumstances, since it would not be to the interests of any disabled person to experience the wish to fulfil a desire which they were biologically inhibited from, but while for most people with disabilities this must be expressed intellectually and reasoned through in course of life choices, for the intellectually impaired it is simply another biological inhibition.

Those with unconscious disabilities therefore, seem to possess emotional attachments and limited capacities for informed desires, but lack much of the ability to apprehend information about their lives and their choices, a lack which often means their choices will be made by others; others who it is hoped both possess the information and capacity they lack and are thus able to make choices which will be of benefit to them. Indeed one major responsibility for those making choices about the lives and preferences of intellectually disabled people, is that they make choices totally in the interests of the person themselves, and not choices aimed at some other goal.[110,111]

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[110] The notion that the interests of disabled people may be subordinated to those of another person, institution, political party agenda, or other goal than their own well-being by helpers, professionals, family members, nurses, carers, or just about anybody else, is one which appears with varying amounts of paranoia or evidence of misuse, directed at one disabled group or another in a huge variety of the literature on the social model.

Titchkosky, French, Smith, Newell and Chappell, to name only a few, have all at one time or another accused various groups, individuals or indeed society at large of attempting to either directly push the interests of disabled individuals aside in favour of others, or convince, by various sorts of coercion, disabled people that other interests than their own take precedence. Some indeed, such as Tassano, even go as far as to accuse the medical profession of intentionally making people believe that they are "sick" and need the care of doctors and nurses in order to maintain their power over others. I will discuss such claims in more detail in the next two chapters, however I do find it rather interesting that while all of these authors loudly protest on behalf of groups such as the hearing, sight, or movement impaired, none of them seem to have recognized that the group most in danger of such subordination of interest is the group who cannot, by virtue of their disability, protest or even understand mistreatment at all. Only French has at all approached this point, however since French's discussion is already couched in such emotive and vitriolic language and seems to roundly accuse most of society of innumerable crimes against all forms of disabled people, this specific point relating to the vulnerability of the unconsciously disabled is somewhat overshadowed.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

We may conclude then that while the lives of those experiencing P.M.L.D. are not entirely dissimilar in the structure of their desire satisfaction to autonomous adults, they can experience at least a degree of desires informed by experience. This on the surface might make the application of the definition offered in the previous chapter extremely difficult, since if P.M.L.D individuals' lives are so different, how can normal degrees of effort or desire frustration be established? Yet, there is another group in society who seem to be in a distinctly similar position.

Children, like P.M.L.D. individuals, have desires which often bear many of the hallmarks of adult desires, but experience reductions in autonomy, in the ability to perceive temporally distant possibilities or engage in some of the more complex forms of second order informed desires mentioned by Griffin.[112]

It is therefore my belief that while comparisons of P.M.L.D. individuals to adults will always appear inadequate, to a large extent due to the profound differences in the quality of life and the relevance in desire satisfaction, if considered alongside children and the experience of childhood, a far richer and more worthy understanding may be established, and one which may also be in line with the previously mentioned definition.

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[111] Tanya Titchkosky.

Also: John Swain, Sally French and Colin Cameron.

Also: Michael Smith.

Also: Christopher Newell.

Also: Anne Louise Chappell.

Also: Fabian Tassano, "Chapter 2", *The Power of Life or Death: A Critique of Medical Tyranny,* (London: Duckworth, 1995).

[112] J. Griffin.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section C: Intellectually disabled individuals and children

Cultural notions of childhood differ widely, whether for instance children are regarded as a form of members of society in training, or as possessing some quality of innocence or purity which emphasizes their need for protection or tuition.[113],[114]Nevertheless, the vast majority of views on the nature of childhood seem to be fairly unanimous on the point that children are firstly, in many senses not to be considered as morally responsible for their own actions and welfare in the same way as adults, and secondly, that it is necessary for others, often parents, carers or other adults, to frequently act as proxy for the establishment of children's life choices in cases where the children themselves may not have the facility to make such a choice.For instance, parents often decide while their child is at a very early age what school the child will go to, reviewing many schools to make the decision, (and sometimes in British society even moving house to be in the catchment area of specifically better schools). This is not a decision, however, which a child just starting school at an extremely young age, four or five years, is able to make for himself or herself simply by virtue of their inability to comprehend all necessary information. A child that young will not fully understand the purpose of schooling or the future benefits of having an education, still less be able to determine how any given school might best provide those benefits. It is thus reasonable and well established that the choice of school is generally one parents will make on behalf of their child.

Of course, it is not true that children's interests and desires are entirely in the hands of others, or that children are completely free of all responsibility for their own actions. Most cultures see teaching responsibility for the consequences of actions, particularly related to the fulfilment of desires, as a key part of the experience of childhood, for instance by encouraging a child to make less critical choices, such as what film to watch, then allowing them to live with the consequence of that choice. Nevertheless, this lack of complete

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[113] There are of course significant variations in the way different cultures treat childhood, see for instance Qvortrup, Frones and Montgomery. Here however, I wish to concentrate on the attributes of childhood which most closely relate to the treatment of those with profound cognitive disabilities and their ability to fulfil desires, namely, the role of parents or other individuals to aid in the fulfilment and comprehension of desires. This is of course not to state that all cultures' views of childhood are the same, or that an Ethiopian child expected to learn adult tasks and participate in society is similar to a Japanese child treated as a precious and pure bearer of innocence. Still, it seems that the difference in capacities, knowledge and power between adults and children, and the responsibility taken for children by adults could be said to be a universal fact of human society.

[114] Jens Qvortrup, "Varieties of Childhood", *Studies in Modern Childhood: Society, Agency, Culture,* ed. Jens Qvortrup, (Basingstoke: Palgrave Macmillan, 2005), pp 1-20.

Also: Ivar Frones, "Structuration of Childhood: An Essay on the Structuring of Childhood and Anticipatory Socialization", *Studies in Modern Childhood: Society, Agency, Culture,* ed. Jens Qvortrup, (Basingstoke: Palgrave Macmillan, 2005), pp 267-282.

Also: Heather Montgomery, *An Introduction to Childhood: Anthropological Perspectives on Children's Lives,* (Blackwell, 2009).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

freedom, and reliance upon others for fulfilling, or in some cases choosing the objects of desire, seems a very well established fact.

At birth, a baby is totally reliant upon those around him or her to fulfil desires, since alone a baby cannot physically fulfil any of them, even a basic desire to change its position. Though it is certainly true that even an extremely young baby is able to form emotional attachments to and, to a limited extent, interact with those around them, particularly parents, it is also true that a baby is in no way accountable for his or her actions or the consequences of desires. It would be unreasonable to expect a newborn baby to refrain from some action, even something as simple as messing its clothes, because the baby's intellectual capacity is simply not well developed enough to comprehend the nature of refraining from action or even, according to some theorists, the distinction between self and other.

From this total and complete reliance upon others, the child slowly accrues both the capacity to decide upon her or his own desires, and the ability to take responsibility for their fulfilment. Though the age at which progress occurs, and even the age of full self responsibility can alter significantly between different cultures, it does seem that there is always a progression in this responsibility for desires, from a baby totally reliant upon others to even interpret what its desires are, to an adult who is able to make his or her desires known to others and responsibly work towards their fulfilment. It is also, therefore, obvious that when thinking of children, one is justified in curtailing desires which may be harmful, in the child's best interest, such as the desire of a young child to put a hand into a fire. This curtailment of desires may not be recognized by the child at the time it occurs even though, if the child had both the relevant information and the ability to understand it, the child would agree, indeed, "You'll understand when you're older," is a phrase not infrequently used by parents, albeit even then, a good parent may still attempt some sort of degree of explanation couched in terms a child can understand, for example "Don't touch the fire, it's hot and you'll hurt yourself".

Since children seem to lack capacities for fulfilling desires and the ability to recognize this lack, a useful schema for examining and understanding the lives of intellectually disabled people might be to think of them not as invariably similar in moral status to fully cognisant individuals, but as essentially possessing the moral status and reduced state of responsibility of children.

For instance, as Griffin notes, since the virtue of choice is itself an intrinsic part of desire, another person could not consign an adult to spend most of his or her time during the day in a set place and location without an extremely good reason; indeed such a restriction, i.e. imprisonment, is usually held to be a punishment.[115] However, in cases where the adult suffers from an intellectual disability that prohibits their decision making process, it may even be a highly moral act, indeed locating a day centre for my sister to attend that she would enjoy, involved a lot of reviewing and careful exploration on her behalf by my parents, in

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[115] J. Griffin.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

much the same manner that a conscientious parent would choose a first school for his or her child.

Like children, intellectually disabled people have reduced responsibility, and are often entirely reliant upon others, particularly if they also possess physical impairments which (unlike a person with no cognitive impairments) they cannot recognize or accommodate for. Also like children, their ability to communicate, and to apprehend their own desires and moral status and their differences or similarities to others, can vary markedly even while still being classed in the same category as "child" simply by virtue of the severity of their intellectual disability. This also very much goes along with the experiences I myself have had with my sister, since my ongoing relationship and interactions with her are far more similar to those I would have with a three or four year old child, than those I would normally have with a person of 21 which is her actual age. Of course this does not demean or diminish the importance of such interactions and relationships, indeed I certainly do regard my sister as important to me, only to note that the nature of my relation to her is certainly not what it would be if she had "normal" intellectual capacities, and should not be thought of as occurring in the same way or form, anymore than an adult's relation to a child is not of the same nature as their relation to another adult.

In my discussion with David Stewart, he fully agreed on this classification, further adding that such a distinction is not one common to legislation or policy on education, since in the British education system enforced status changes ,such as leaving school at the age of 18, can have profound, and often dire consequences on the lives of intellectually disabled people, even though such a distinction as the age of 18 means comparatively little for someone whose approximate age and mental capacities remain those of a much younger child. Simple and fairly obvious as this move may be, I have found no one anywhere in the literature I have examined who takes this route, in fact, as previously noted, very few authors on disability wish to engage with the subject of intellectual impairment at all, despite the intellectually disabled being one of the groups most in need of theoretical representation due to their inherent inability to interact with those around them. Indeed I partially desired to include the subject of cognitive impairment in my overall discussion of a new definition of disability precisely for this reason, that the majority of literature (especially from the perspective of the social model), miss them entirely, despite the fact that legislatively and socially our common understanding of "disability" does include cognitive disabilities, and that as a group who categorically cannot represent their own interests they require far more theoretical attention than more politically active groups of those classified as "disabled". There is, however, one extremely important aspect in which children and those with intellectual disabilities differ markedly: Children grow up!

In considering the needs and desires of children, it is necessary for anyone to consider the fact, sometimes obscured to children themselves, that they will eventually cease being children and certain decisions taken in childhood will have a large and more long lasting effect over the course of their lives. For example, while it may be reasonable from a child's

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

perspective to not attend school and spend the day playing, in terms of attaining educational goals which will later be of much greater benefit this is not advisable, hence why an adult needs to often encourage children to attend school even against a child's other inclinations.

This concern however of recognizing children's ability to alter their capacities over time, does not apply to people with unconscious disability, since, by the very nature of what their disability is and the reduction of their capacity for self-assessment, they cannot and will not be able to change their circumstances in the future. Like Peter Pan, they would seem to literally be children who never grow up, and as such the values which should be used in understanding their moral status show some differences from those involved in the consideration of "normal" children. Since these differences bear heavily upon the environment of children and a comparison of their lives to those with unconscious disabilities, it will be necessary to appeal to the theory of environmental comparison I established in the first chapter to resolve them.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section D: Unconscious disability, children and conceptions of the "normal"

In much of the anthropological work on children I have surveyed, most anthropologists have focused exclusively on children as slowly gaining cultural practices and status throughout childhood.[116] Childhood has, as Montgomery observes, in many cases simply been seen as a time when children have neither acquired the biological maturity nor necessary understanding of a given culture's values to be thought of as fully developed members of that culture, an acquisition often marked by some sort of coming of age ceremony or ritual.[117]

In the 1970's however, through the work of psychologists, sociologists and anthropologists taking a more humanistic approach such as Piaget and Gregory, the idea of childhood changed. Children were no longer simply a half full glass of cultural value which slowly filled up over time until the child was finally able to go through the appropriate rites and be accounted a fully equal member of a given society.

Under Gregory's view (a view with such modern exponents as William Corsaro), children were part of what could be thought of as their own culture and environment, unique and specific to children with its own individual set of values, rules and proprieties existing even at the same time as children learned and were introduced to more adult values.[118]Thus, as well as accruing adult experiences and learning the appropriate behaviours and standards of a given culture, children could be considered fully aware and conversant members of "The culture of childhood". Corsaro indeed, took the step of quite literally posing as a child in several nursery schools in America and Italy, where he encouraged the children to think of him as "Big Bill", i.e., as another child (albeit one of larger stature) rather than as an adult. He did this in order to participate in, and understand the "culture" of, childhood in much the same way as other anthropologists would study a culture by living within it for a short amount of time.

Corsaro's findings were that children's behaviour among other children involved not merely an aping or playacting of half learned adult behaviours, but many acts, such as

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[116] Allison James, "Life Times: Children's Perspective on Age, Agency and Memory Across the Life Course", *Studies in Modern Childhood: Society, Agency, Culture*, ed. Jens Qvortrup, (Basingstoke: Palgrave Macmillan, 2005), pp 248-266.

Also: Ivar Frones.

Also:Heather Montgomery.

[117] Ibid

[118] William A. Corsaro, "Collective Action and Agency in Young Children's Peer Cultures", *Studies in Modern Childhood, Society, Agency, Culture*, ed. Jens Qvortrup, (Basingstoke: Palgrave Macmillan, 2005), pp 231-247.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

spontaneous and instantaneous role-play, the construction of fantasies, or the changing relations and formalities existing between groups of children, that were unique and specific to the experience of children in that setting. Such experiences could not be directly acquainted with the teaching children had received from adults or from wider social practices they may have observed, and seemed entirely unique to the experience of childhood itself. Thus if we treat childhood as possessing its own distinct identity as a state of being and a cultural environment, the consideration of cognitively disabled people as "children" seems to become extremely clear in exactly what ways the cognitively disabled differ from the "normal", i.e. those adults who are optimally equipped for the fulfilment of desires within their environment and how their desires, experiences and abilities to relate to others should be assessed: not as merely the sentimental postures of a doll, or yet as a disabled individual who is aware that they are denied fulfilment of desires, but as a child with the desires, capacities, limitations and cultural identity of a child.

We can now apply the acid test for normality, i.e. comparing the intellectually disabled individual to a child in a similar isolated castaway circumstance, in order to then establish rules, variations and ultimately the nature of the respects in which their lives are limited. For instance, though a three year old child and a fifty year old man with impaired intellectual capacities may be equally unconscious of themselves and the world around them, and equally happy playing with a set of toy bricks, the three year old child has the clear possibility of being able to grow into an adult who is more able to take responsibility for and fulfil his or her own desires. Thus, the play with bricks takes on another meaning for the child which it does not have for the intellectually disabled man, since for the child learning the physics, spatial awareness and basic knowledge of objects, which will come from playing with the bricks, holds value beyond their immediate pleasure, whereas for the disabled adult it is the desire to simply play with bricks that is satisfied in this case. This is, however, not to say such a desire is in itself reduced in its effect to provide pleasure through fulfilment, but the three year old child, when viewed from a temporal perspective, would seem to have a far greater value in playing with the bricks than an adult. We may therefore categorize the limitation on the lives of intellectually disabled people as a "temporal impairment" in rather the same way that, while all humans are, for roughly the first year of life quadriplegic, only actual persons with quadriplegia will be forced to remain in this state throughout the rest of life.

Thus, it is argued that the desires and lives of those with levels of P.M.L.D. should be considered not according to a comparison to the fulfilment of desires of an adult, but a child. Indeed in many ways the P.M.L.D. state places a child in a far more difficult position since they lack the capacity of self-analysis and later retrospective judgement of their own experiences and thus are far more at the mercy of desires being frustrated, e.g. while a normal child might be able to later say, "Mr. Jones was a bad teacher since he stopped me doing art," a P.M.L.D. individual will later never get that retrospective judgement, and thus will simply have the desires of childhood, and its activities frustrated or aided by those around them.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

It is also easy to see on this schema how the legal restriction of altering the lives of intellectually disabled people at the age of 18, or forcing them to follow a set national curriculum in school is a harm, since we would not expect, in normal circumstances, a child of a similar intellectual state to follow such rules.[119] One issue with this schema is that quite evidently, as Mary Warnock noted, intellectually disabled people can learn a degree of control over their lives analogous to that of a child of a similar age, for instance it is possible for my sister to say "yeah" and "nah" to answer any questions she understands such as "do you want a drink?"[120] Because, however, of the lack in cognitive capacities, such teaching will necessarily be limited in what it can achieve. This is of course not to say that such teaching or experiences of freedom are not in themselves equally valid and valuable to intellectually disabled individuals simply by virtue of their ability to bestow an experience of freedom. My sister completely enjoyed using an electric wheelchair, and loves the ability to use large, easy to handle buttons to turn off and on her own videos. Neither of these served any purpose but the enjoyment of freedom, albeit a purpose that is fully worthy in the context of the desire applied to a child.

This perhaps shows the key difference in considering the lives and desires of intellectually disabled people, that though they seem to be children bearing a temporal impairment, and that certain decisions and assumptions connected with childhood and development seem to not apply, many others, such as their ability to participate in the culture of childhood, enjoy the rhymes, stories and play of childhood and experience the freedom implicit in exacting control over the world are very much prominent and thus worthy of respect, particularly if we consider those with cognitive disabilities not as disabled adults who lack some sort of undefined intellectual attribute but who should nevertheless be treated as responsible adults, but as children who have literally suffered a temporal impairment, which frustrates, or indeed in many cases completely removes their capacity to cease being children.[121] Thus, in any case in which we consider the lives, desires and responsibilities of cognitively disabled people, who are unconscious of their disability and will remain so, it is necessary to view them as children, and children worthy of consideration and empathy.

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[119] It is unfortunately true that in many schools in Britain, children with cognitive impairments are forced to endure circumstances intended for children of much older age groups, and that their status utterly changes at the age of 18. Indeed some of the worst experiences my sister has had have involved her being in the care of those who focus on age rather than actual desires and will for example play her pop music that would appeal to teenagers, rather than directly considering her own desires and understanding.

[120] Mary Warnock.

[121] Of course, my suggestion here is not to imply that "child" is in any sense an absolute state. Some children may enjoy engaging in adult activities, and as noted, control and education have purposes at almost any level of childhood. However, it is hoped that by having the category "child" in mind when considering intellectual impairments rather than defaulting to "adult" a more reasonable and flexible system for valuing and understanding the desires and experiences of intellectually disabled people may be achieved.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

In using the comparison to children and the distinction of temporal impairments, the definition offered in the previous chapter is able to provide something that the social, and medical models have lacked, a method for considering the desires and relative state of environment of cognitively disabled people, and understanding in a practical and on a case by case basis, exactly what is required for their well-being. To remain (ironically), "unconscious" of them, as so many commentators in the social model are, misses a fundamental aspect of what disability is.

If the intention of discussing the definition of disability is, as Davis and Goering both suggest, the removal of some sort of "ableist human paradigm" and the setting up of some kind of pro-disability self-identity, then it is true there is no room in this discussion for those who are not conscious of their disability.[122]

As I have noted, however, the inadequacy of the social model's response in accounting for the needs, desires and well-being of those with cognitive impairments is fundamentally missing a part of what our current understanding of "disability" is. If indeed the intention is to remove a "ableist paradigm" and replace it with a "disabled paradigm" then where on this scale do those currently categorised as disabled but unable to recognize themselves as such fall?

Since, however, my intention here is to clarify our existing intuitions regarding "disability" and to formulate a definition which allows discussion of disabilities, rather than preclude it to some pre-existing political groups and their ultimate goals which may exclude certain types of disability, then engaging with temporal impairments and the questions of unconscious definition is critical to that project, i.e. as legislatively, intuitively and logically we believe people with P.M.L.D. to be disabled, any definition of disability must take time to examine in what ways they might be disabled and endeavour to formulate models, language and tools that may be used to discuss and promote their well-being.

This is why the comparison to the moral status of children, and understanding the desires and well-being of those with P.M.L.D. with respect to this status, is a necessary step in applying the definition of disability based on well-being to those who are so often usually outside disability discourse.

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[122] Sara Goering.

Also: N. Ann Davis, "Invisible Disability", *Ethics,* vol. 116, no. 1, (October 2005), pp 153-213.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section E: Conclusion

In this chapter I first established the nature of an unconscious disability, and distinguished it from the state of unaware disability, i.e. the unconsciously disabled who is in such a state that he or she will never be aware that he or she belongs to a distinct disabled group or differs from other members of society.

I then considered the scant literature on the subject and showed some of the very inadequate attempts the social model has employed to deal with this aspect of disability.

Next I examined the desires and life of people with unconscious disabilities, who usually fall into the category of the profoundly intellectually disabled, and considered in what ways their lives could be valued.

Finally, I established that by comparing the intellectually disabled not to adults, but to children, a far more logical and useable framework of reference may be created to discuss their needs and desires, and also it may be seen how through temporal disadvantage they are disabled in respect to children, and why I believe this discussion to be so critical to the application of any definition of disability.

In the next chapter, I shall take the definition I established, along with the modification I have made here regarding intellectual disability, and look at some of its practical and social implications.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Chapter 3: Applications of the definition: accessibility and the relations of empowerment

Introduction

In the first chapter it was established that the defining characteristic of disability was not its social identity or its medical classification as part of a person's bodily health, but simply the ways in which disability affects a person's well-being, i.e. the fulfilment or frustration of their desires throughout life, and how much effort it takes to fulfil those desires. Having established this on a purely theoretical basis, it is now necessary to examine precisely how this definition may apply when considering exactly how disabled people's lives are lived, how their desires are fulfilled or frustrated and what measures and mechanisms may be employed to circumvent the difficulties of unfulfilled desires caused by a disabling condition. Hopefully by making a detailed examination of disability simply in light of its effects upon desires and well-being, rather than specifically its social or medical relations, it will be possible to learn in what ways the well-being of people experiencing disability may be improved on a realistic, practical basis, and the problems or pitfalls associated with such improvements.

Of course, measures for alleviating the bad effects of disability are already familiar features of our social or ethical landscape, thus a good part of what is suggested here may be more in the matter of refinements or clarifications of some existing concepts, such as accessibility or assistance, than suggestions which are completely and entirely new. Using a definition of disability that is based upon desire and well-being, however, will, it is hoped, provide a far more straight-forward approach to evaluating such concepts, and a more relevant set of tools to decide how well such concepts actually work in practice. For example, while the idea of accessibility is one which is familiar in fields from the building trade to economics, thus far few discussions of making a thing "accessible" have related that accessibility to any discussion of effort.

As noted in Chapter 1, there are two principal ways that a disabled person, experiencing a desire whose fulfilment is adversely affected by their disability, may respond in order to fulfil the desire. They may either employ some external agency that enables the desire to be fulfilled irrespective of biological limitations, whether that is a human or animal assistant, or an inanimate piece of technology such as a wheelchair, or by altering the conditions under which that desire counts as fulfilled in such a way that the biological limitations of a disability still allow the disabled person to fulfil it.

I will consider the first of these questions in Sections A, B and C, dealing first with the circumstances surrounding the uses of inanimate aids to fulfil a desire, and then in Section B with the unique problems associated with the use of a human assistant.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

In Section C, I will add a brief note on assistant animals, their relationship to a disabled person, and the ways in which they differ from human assistants and technology in aiding desire fulfilment.

In Section D, I will turn to the conditions surrounding desire fulfilment and attempt to establish principles under which it may, or may not, be reasonable for a disabled individual to alter their desires, or indeed the conditions under which their desires are fulfilled to compensate for biological limitations, as well as when it is reasonable for such alterations to be proposed and who has the right to propose them.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section A: Accessibility and external agency

In the social model, as noted by many commentators, the intrinsic misfortune of disability and any detrimental effects it has on a person's life are held to be largely a matter of society's overall view of disabled people, rather in the way that the detrimental effects of belonging to a racial group suffering discrimination are not physically identified with belonging to that race, but with the way society treats members of it.[123]

As noted in the first chapter, however, this contention that a disabled individual's disability is essentially as neutral a characteristic when it comes to the fulfilment of desires, as, for example, skin colour or accent, does not seem to fit with the facts.Whatever society's actual attitude is, biological limitations seem to be implicit to the body and the self, rather than being imposed externally by social pressures or practices.

Thus, in America up until the 1960's, the laws of the prevailing establishment forbade so called "Negros" from playing basketball in a similar mainstream arena to "white" players. There is no intrinsic reason why possessing darker skin should affect a person's ability to run, jump or throw a ball. The only restriction in this case was entirely created by the society of the time. There is however no similar rule that states categorically that a person with paraplegia cannot play basketball, the restriction here is set by a person with paraplegia's biology, since as it stands, the ability to run is implicit in playing basketball and that is an ability a person with paraplegia does not have simply by virtue of their paraplegia.

Furthermore, there are cases where a disabled individual, rather than being directly excluded, as in the case of the paraplegic person, is simply in the position of having to

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[123] It is not just the Nazis who argued for the qualitative difference in the lives of people of various racial groups. Even recently, some statisticians such as Michael Eysenck[123a] have put forward the idea of differences in racial intelligence, characteristics such as musical understanding or emotional empathy, social responsibility and even overall standard of living. Given major differences in the social and cultural conditions of different racial groups, it is, however, extremely unclear whether any perceived differences are due to racial factors at all, or merely due to differences in environment.

Then, as with any sets of statistical differences, any difference is shared by the group and not by an individual, thus being of one racial group said to be overall superior in one factor, would not automatically mean that belonging to that group endowed a superior amount of that factor, which would mean at most that being of a different racial group gave a slightly increased chance of possessing a given characteristic, not that a person would necessarily possess it, just as it is true that while most people born in England speak English as a first language, not all do. Then of course, even if the question of, for example racial intelligence, had a definitive answer, whether this equates to well-being is a far more complex matter and not one with a clear and distinct answer either.

For purposes of comparison, and because racism is itself an intrinsically social phenomenon, I will leave this question aside and assume that different racial individuals are (with the exception of their individual differences) innately similar in their capacity for well-being.

[123a] H.J. Eysenck, *Race, Intelligence and Education* (London: Temple Smith in association with New Society, 1971).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

expend such a large amount of effort in performing the necessary steps to fulfil a desire, it would prove ultimately to be pointless. A blind person possesses the abilities to run, jump, and dribble the ball by hand, however in order for them to play basketball vast amounts of time memorizing the court, calculating precisely the location of the basket, not to mention an extreme concern of colliding with other players, would make such a desire far more trouble and effort to fulfil than for a person with normal vision. Again, this effort factor is not imposed upon a disabled individual by society, but part of their intrinsic nature and capacities, though undoubtedly society could aid in fulfilling such a desire, a fact I will return to later. This is indeed why many disabled individuals choose to only take up part-time jobs, since the effort costs required of full-time employment would mean a disabled individual, even one whose disability was primarily physical rather than based on fatigue, would not be able to undertake many other desires that they may wish to fulfil.[124]

Many writers in the social model, (Silvers, Darke, Swain and French), have for a long time protested for "access" by which they usually mean the availability of resources to make it possible for a disabled person to fulfil a given desire and usually, as in the case of Roulstone, a desire common to many individuals in society such as the desire to perform a job, have access to reading, or indeed access to freedom of travel.[125,126,127]

Frequently, the method chosen for this access by social theorists, disability campaigners and indeed those involved in any form of dialogue with individuals regarding a disabled person's fulfilling of desires, is via the means of altering part of the environment, or

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[124] Alan Roulstone, "Researching a Disabling Society: The Case of Employment and New Technology", *The Disability Reader: Social Science Perspectives*, ed. Tom Shakespeare, (London: Continuum, 1998), pp 110-128.

[125] Anita Silvers.

Also: Paul Darke.

Also: John Swain, Sally French and Colin Cameron.

[126] Though some of the more radical social theorists such as Titchkosky, Germon and Barton protest that the social model is not primarily motivated by political ends, but by a "different, non-ableist phenomenology", this position is usually only arrived at after long discussions of more practical matters of access and fulfilling desires, and for many social model theorists it is the intrinsically political ends of the social model (i.e. making social changes to allow disabled people to fulfil desires) that is the main thrust of the enterprise, indeed some activists like Germon feel academics working on disability theory have somewhat missed the point of the social model in the first place. Thus, access may be said to be the cornerstone of the social model, albeit that it is assumed any lack of access is due to society only, rather than being attributed partially or entirely to a disabled person's physical or mental condition.

[127] Tanya Titchkosky, "Chapter 8".

Also: Penny Germon.

Also: Len Barton, "Sociology, Disability Studies and Education, Some Observations", *The Disability Reader, Social Science Perspectives,* ed. Tom Shakespeare, (London: Continuum, 1998), pp 53-64.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

through the use of technology. Using an embosser (a Braille printer), to provide written materials in Braille, installing a lift to allow wheelchair access to buildings, indeed on one level, wheelchairs themselves generally as an alternative to walking, as well as the inclusion of subtitles in films and other inclusions of written rather than spoken information, are all examples of ways in which technology can externally influence the desires of a disabled person by altering the conditions of the world around them so as to make a desire easier to fulfil.[128,129]

The thinking behind this form of external modification of the environment seems very straight-forward on the surface: Jane has a given desire, but one or more of the requirements for fulfilling this desire is biologically beyond her capabilities. Thus, by effectively altering Jane's ability to interact with the object of desire by employing another external object or agency, Jane's own biological limitation is no longer an obstacle to fulfilling her desire. On closer examination, however, it seems the issue of using technology to enhance accessibility is not nearly so simple or clear cut as it initially appears. Firstly, there is the question of effort, a question I touched upon in Chapter 1. Thus far comparatively few solutions to disability based desires have been able to reduce the effort required by a disabled person in the fulfilment of a desire to approximately the same degree as that of an able bodied person.

To use an everyday example, as noted previously, while a wheelchair and a ramp may be sufficient to ensure a person with paraplegia is not utterly barred from going up-stairs, it will still take them more time and muscular work to do so than someone ascending the same distance on foot, which will have correspondingly greater effects on what other desires they may be able to fulfil during the rest of their life. This is one aspect of the problem of accessibility rarely even accounted for by social theorists, and yet it has very real and practical consequences in any dialogue concerning the use of external agencies to augment desires.

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[128] Of course, another major factor involved in the use of technology, and one which will heavily influence an individual's decision to use or not use such devices, will be a person's own perceptions of his or her independence, and any social assumptions or attitudes attached to uses of that technology. Though this is undoubtedly a hugely important factor in the use of external aids and devices, it is one entirely divorced from the function of the technology itself or its capacity to fulfil desires. I will return to this aspect of technological assistance in Chapter 4 when I consider disability and social attitudes.

[129] Goering takes the significance of inaccessible aspects of life rather further by claiming that society itself sets the conditions under which lives may be lived and desires fulfilled, and that "accessibility" is only a minor recognition of this fact which doesn't go far enough in examining the "Ableist thinking" implicit in society. I will return to Goering's suggestion about society constructing the environment, or at least setting the fulfilment conditions for desires later, though it is worth noting at this point that, even though Goering argues fervently for a radical reconstruction of the social environment and against providing access to an existing socially constructed "ableist" one, her actual recommendations such as altering shops to make them less threatening and inconvenient to those with a mental illness or with mobility problems might as well be couched in the language of accessibility, since they practically come down to the same thing just made with a degree of additional rhetoric.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

For instance, my bank recently started employing security questions about the balance and status of my account when I use telephone banking. When I explained that the very reason I wished to use telephone banking in the first place was because I was unable to read conventionally printed bank statements, their solution was to provide a bank statement in Braille. A Braille statement not only wouldn't fit through my letter box, but since it takes approximately 15 minutes in Braille to read an average A4 sheet of print (bearing in mind skim reading is not possible in Braille), reading the statement would take me about 45 minutes. Yet, according to my bank, they had provided an "accessible" alternative, and would not consider other options of getting my bank statements to me for that reason.

These types of situations, where the effort costs of the fulfilment of a desire are massively altered by a person's disability even where an external technological solution has been introduced to make the desire supposedly possible to fulfil, occur with worrying regularity in the lives of disabled people, and are often not commonly recognized in society. It is believed for instance, that asking a wheelchair user to go a long way around the back of the building to find an accessible entrance is a reasonable form of accessibility, despite the extra time and effort required, (indeed often a disabled person who points out this fact is thought to be ungrateful or pushy, a point I will return to in Chapter 4 when considering social attitudes). This is because "accessibility" is usually held as simply "have access to", i.e. be available as a possible alternative course of action or alternative choice, saying nothing of the effort or desirability of that choice.

For instance, a place that is said to have "road access" simply means that a person can drive there. It is not implied that travelling to such a place by road is easy, or that driving is easier or harder than walking, simply that as one method of getting to a given place, if it has "road access" a car is a possible choice of travel. If the purpose of accessibility, i.e. introducing external changes into the schema of a disabled person's desire, is to provide them with "equal opportunities" as many forms of literature and current governmental thinking put it, then not merely the basic biological access to the fulfilment of desire must be provided, but also an attempt to equalize the amount of effort required by a disabled person to fulfil the same desire.

As noted in the first chapter, if a disability is an involuntary biological state of a person that adversely affects their ability to fulfil desires, then the purpose of equalizing technology must be to compensate for this biological lack, but not merely by making a desire "possible" but "possible with approximately equal effort". Thus, it is not only necessary that a building has a wheelchair entrance, but that in order to be truly "accessible" that wheelchair entrance must (as much as possible) not require greater effort on the part of a wheelchair user to enter than climbing the steps.

One serious problem however in the definition of effort as a factor, is that even between "normal" humans, the effort involved in carrying out a desire will be greatly unequal, for instance a person in their 70's will have far more difficulty running a hundred

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

metres than a person in their 20's. As noted in the previous chapter however, in one sense many humans at one stage or another may be thought of as disabled, i.e. biologically precluded from carrying out desires, indeed it is quite possible that the 70 year old may be disabled in some respect (many elderly people use external devices such as walking frames for this reason). How then, would it be possible to create a category by which to compare the effort costs involved in carrying out a given desire, and thus establish what work must be done by an external agency in aiding a person in that desire's fulfilment? To answer this difficult question, it will be necessary to return to the example of the castaway mentioned in the first chapter.

A castaway divorced from the action of society has nothing but his or her basic biological equipment with which to fulfil any given desire, thus for instance a dark skinned castaway would seem to be on an equal footing to a light skinned one. However, as noted by J.R. Lucas, all humans are not equal, and skin colour is only one comparatively unimportant factor in a person's biological make up which may affect their fulfilment of desires, and the biological nature of different humans may vary widely.[130]

It is however not the purpose of the castaway example to create some sort of ideal standard by which humans should be measured, indeed, as J.R. Lucas notes, the establishment of such a standard may be impossible, as all humans are to some degree imperfect in their ability to fulfil desires in some area. As noted in Chapter 1 however, the castaway thought experiment is rather a tool to be used in the testing of different humans against each other, rather than some ideal way to compare all humans.

So, the question under discussion is not "is a 70 year old unable to run 100 metres in some sort of ideal average time in need of a walking frame?" but "is a 70 year old unable to run 100 metres as quickly as a 30 year old in need of a walking frame?" Obviously, different 30 year olds will take different times, however it is not the purpose of the castaway test to establish an average time for running 100 metres, but instead to observe whether there is a general difference in the two groups, i.e. those categorized as disabled or with some sort of biological condition, including bodily condition due to age, and those without it.

So the issue is not whether a given person is better at performing any desire, but whether the average of humans who enact that desire perform it with more or less effort with or without a disability. Indeed, this inequality due to biology is exactly what the disability itself is, a preclusion of desire fulfilment which one group of humans has due to their involuntary characteristics, and which another (the larger group) does not. More broadly, this may be compared to the scientific process (often used in medicine)of postulating ranges of averages for different biological groups, for example a minimum and maximum heart rate for people in their 20's, though obviously it is the purpose of the castaway thought experiment to compare the effort involved in the carrying out of different desires. By taking any given

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[130] J.R. Lucas.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

desire, and performing a non-biased comparison of effort in this way, it is possible to see the inequities involved in given situations, with or without technological agency, and thus establish the nature of what modifications may need to be enacted to alter the needed effort in the desire fulfilment of a person with a disability.

It may also be seen therefore that the definition established in the first chapter is not a static, monolithic concept by which disability is singly categorized from ability, such as a species definition, but rather a theoretical definition of the word which establishes the tools under which any given interaction between a person's involuntary biological state, the state of the world, and the fulfilment of their desires can be measured. Indeed, it is in the performance both individually and on a more global level of this evaluative process that the nature of disability itself exists, i.e. it is not correct to say that person x "is disabled", but rather that person x is "in a state of disability" in any given time or set of circumstances.

This is also obviously a key way in which disability differs from racism or sexism, and "being disabled" should be thought of as closer to a concept such as "being lost", i.e. a temporary or permanent relation possibly with a group identity, possibly without, that adversely affects a person's relationship to his or her fulfilment of desires, though the nature of disability and society is something I will return to in the next chapter.

So, taking "accessibility" as to include the concept of effort, in looking at a person with paraplegia's desire to enter a building, if he or she has a far longer journey around the back of a building to an entrance, and a harder time pumping his or her wheelchair up a ramp than a person who can merely climb up a short flight of steps to the door, it is obvious to see that though the paraplegic person may have access to the building, i.e. he or she can enter it, the establishment of equality for the person with paraplegia in making the building "accessible" has not been met.

Another major concern in the matter of effort and accessibility, is the question of disabilities which may not actually involve the direct biological preclusion of a desire, but simply through pain, stiffness, or other forms of strain make it far less possible to carry out with the same amount of effort as a person who did not experience those biological conditions. Many people in such situations may have desires that, while not precluded directly, may simply involve an excessively high effort cost which makes their fulfilment an unreasonable expenditure of time and trouble. This is where the use of the castaway example and a definition of disability which incorporates effort can be of valuable help, in establishing when at any given time a biological condition is contributing markedly to the effort costs of a person's desires, and when a person should indeed consider using some form of external device or agency, whether the condition is a temporary one such as a broken leg requiring the person to use a crutch to walk, or a permanent one such as arthritis.

For instance, a person experiencing increasingly more strain peering at smaller print with a degenerative eyesight condition, such as retinitis pigmentosa, may need to compare his or her own effort, pain and trouble involved in viewing smaller objects, to those of a person

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

without such a condition, and when the costs involved in such effort become prohibitive perhaps consider technological assistance like a magnifier or screen reading computer program.[131],[132] Comparisons to others in such situations by those around the disabled person or by the disabled person themselves, for example "it's taking me far longer to read that newspaper than Jack", are in fact already common throughout life as personal decisions undertaken by those with disabilities (Carel's increasing use of breathing aids in the face of her degenerative illness is a very well illustrated and moving example).[133] Though the formal use of the castaway test may aid in these situations by deciding precisely what forms of external aid are required, and also deciding how effective a given external change is for the fulfilment of a desire.

Using the idea of the effort involved in carrying out desires, rather than the more common notion of simply "access" divorced from effort, it is also possible to recommend accessibility changes for conditions not usually associated with them. For instance, a person experiencing agoraphobia would greatly benefit from the ability to do their shopping at home across the internet, since the amount of effort involved in them going shopping would be far more than a non-agoraphobic person, though this sort of access change also applies to anyone with movement difficulties as well.[134]

So, accessibility can be said to be the employment of external agency or factors (i.e. factors not involved with changing the person's physical or psychological being), which contribute to either removing or reducing biological limitations to fulfilling a desire, or reducing the effort required for fulfilling that desire to the same amount experienced by a

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[131] In British policy on disability by the National Health Service or other bodies, provision of "aides and assistance" is often the first response to the diagnosis of a disability. This refers to wheelchairs, personal devices such as a white cane, glasses or a hearing aid, however in my category of external agencies to aid the fulfilment of a disabled person's desires, I would also include more large scale modifications such as a ramp to a building or the provision of subtitles, as both are external, i.e. outside the person's body and connected with the world, and both have the function of aiding a disabled person in the fulfilment of desires.

While some devices such as a wheelchair or white cane also have a social function in the identification of disabled people (and according to commentators such as French and Darke, their stigmatization and mark of segregation) here I am only concerned with the function such items have in the fulfilment of a disabled person's desires. Any social ramifications will be examined in Chapter 4.

[132] John Swain, Sally French and Colin Cameron.

Also: Paul Darke.

[133] HaviCarel, "Chapter One", *Illness: the Cry of the Flesh,* (Acumen, Stocksfield, 2008).

[134] There are some psychological techniques such as systematic desensitization that would expressly require an agoraphobic person to get used to going outside, and it may be recommended they take the extra effort in shopping as part of reducing the more general overall effects of their condition, i.e. curing it. This, however, is not connected with access specifically, since the desire to no longer suffer agoraphobia is a different one from the desire to make purchases from shops, with different effort conditions for fulfilment.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

hypothetical individual with no similar prohibitions, divorced from society, fulfilling the same desire.

At our current rate of technology, external agents used to aid disabled people in the fulfilment of desires are at best an imperfect solution. As noted, the effort costs of using such agencies are often high, and such external agencies, especially when they take the form of the alteration of an object or location in the world rather than a device under the direct control of the disabled person, may not be consistent. For instance, some public buildings may have wheelchair ramps and some not, and some bus services may provide audio announcements to stops and some not.

In fact lack of consistency may make such alterations useless, as a disabled individual may not wish to gamble on such alterations being present so may not be able to make reliable use of the ones that are there. I myself never use buses for this reason, as only some announce the stops in audio, and I do not wish to risk finding myself on a bus with unknown stops. It may even be argued that when an accessibility measure is accompanied by this sort of inconsistency in its application, the "effort" involved in taking the risk, and the anxiety of, for instance arriving at a building that one is unable to enter, or being provided with audio only material that one cannot access, denigrates or even completely negates any possible equalization of effort that the accessibility measure is intended for in the first place.

Of course, technology, environmental alteration, and other forms of external agency are only some of a number of methods by which a disabled individual may fulfil a desire. Another, and one commonly examined and criticized by social theorists, is the use of another human being as an assistant in fulfilling a disabled person's desires.

By Luke Hewitt

Section B: Accessibility and assistance

The idea of a human as an assistant, guide, carer or otherwise provider of help to a disabled individual, though it appears an intrinsically simple one, is one of the most frequently debated issues in disability theory.[135]

Social theorists, such as Swain, French, and Brisenden, all claim that, to a greater or lesser extent, the idea of receiving help or care is basically a negative, paternalistic state. The person cared for automatically stands in a more dependent and powerless relation to their able-bodied assistant, a relationship often believed to be intrinsically attached to the "disability as illness" thinking of the medical model.[136] Many theorists, such as Newell, Shakespeare and Titchkosky, have hotly debated that words like "handicapped" and even "disability" imply a state whereby one person is automatically existing on the charitable action, or under the care of, another.[137] Some social theorists contend that the word "handicap" is derived from "hand in cap" i.e. putting money in the hat of a disabled beggar, while some hold that even the word "disabled" is one which implies a state of increased dependence upon others and so prefer terms like "differently abled" or "impaired".[138]

Though the 2002 Disability Governmental Survey did show that many people did not wish to consider themselves disabled since they believed it intrinsically implied helplessness, this is perhaps exactly why a new definition of the term is needed and an examination of the supposed dependent relationship between the disabled person and any human assistant they require in a less negative light.[139] After all, if one holds the broader idea of "disability" as being a state which will at some point affect most humans throughout their lives, then the implication of the term "disabled" seems to lose a lot of its uniquely negative emotive impact,

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[135] Social theorists usually use the terms "agent" and "patient" to define the roles of the assistance relationship, and indeed criticize the relationship on the basis of those roles, i.e. the patient is passive and stands in a relation of lesser power to the agent. Since, however, I wish to examine the relationship more fundamentally and dispense with bias caused by medical labels, I will use the terms "assistant" and "recipient" instead, which it is hoped, are more functional and less loaded.

[136] John Swain, Sally French and Colin Cameron.

Also: Simon Brisenden.

[137] Christopher Newell.

Also: Colin Barnes, Geoff Mercer, and Tom Shakespeare.

Also: Tanya Titchkosky.

[138] R.B. Jones.

[139] Ini Grewal, Sarah Joy, Jane Lewis, Kirby Swales, and Kandy Woodfield, "'Disabled for Life?' Attitudes Towards and Experiences of Disability in Britain", *Research Report* 173, (Department for Work and Pensions, August 2002).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

since "disabled" becomes, not automatically a group of powerless individuals to which some people are condemned to belong, but a group with an unfixed membership standing in a relation to their environment and the people around them, which is much closer to "being lost" or "having an accident": unfortunate, but not out of the ordinary or in any sense demeaning to the one who suffers such misfortune.[140] So, for most social theorists, the fact that a person is "disabled" and consequently receives assistance in their lives from another person, automatically implies that the disabled person is in a subordinate relationship to those providing that care or assistance.

Some writers, such as Szasz and Tassano, have taken this concept to a quite extreme level and claim the medical profession, either deliberately or accidentally, maintain the "doctor/patient" relationship specifically so that they can hold privileged access and power over the patient themselves, as well as over society at large.[141] Swain also notes that the idea of a disabled person as the recipient of "charity" undermines their own autonomy and control over the course of their life, while putting the disabled person (as Smith argues), in a relation whereby their own desires and well-being are subsumed to those of the "carer" (either a medical professional or a family member).[142] It is common when reading any account of disability written by a social theorist like Swain or Smith, even Titchkosky, to note an extremely strong reaction against any sort of human assistance in the fulfilment of desires, and the implication that to have a human fulfil such a function is always damaging in some way to a disabled person's life, indeed some, such as Smith and Germon, go even further and rank such relations as very literal "oppression".[143]

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[140] How a word is perceived and what its derivation might have been in the past, is an incredibly different matter to how it is used now. For instance the word "woman", some believe, had a derivation of "half man" and thus an automatic implication that women are less than men, and it cannot be denied that there were situations in the past when the word "woman" automatically implied subservience and dependence upon other. It is, however, the task of philosophers and ethicists to examine uses of language and establish precise and useful definitions that will, it is hoped, reject any such unethical uses of language in the past. Thus, just as it is hoped now the word "woman" means "female human" with no other negative connotations it is hoped that the redefinition and precise examination of disability which I am offeringin this thesis will allow relations such as dependence to be rethought, irrespective of the older derivations or implications of the term.

[141]Thomas Szasz, Fabian Tassano.

[142] John Swain.

Also: Michael Smith.

[143] John Swain.

Also: Michael Smith.

Also: Tanya Titchkosky.

Also: Penny Germon.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

In these many criticisms however, the social theorists do seem to have failed to ask two basic questions about the nature of human assistance. Firstly, "What exactly is the intended purpose of this "care" or assistance?" and secondly, "Is the recipient automatically made powerless by receiving it?"

In their criticisms of "care" or "assistance" as a concept, social theorists usually assume that it follows the model of nursing. A nurse is defined as a trained medical professional responsible for the well-being and continual health of a person who is ill, i.e. who is suffering some form of physical malady (see Chapter1).[144]

If a nurse is, however, responsible for insuring the "well-being" of a person who is ill (or disabled), the person's "well-being" must logically include the fulfilling of desires, and therefore, as Griffin argues, the freedom to make choices about those desires.[145] Indeed some nursing training materials define the role of a nurse not as a dictator, who determines what will happen to the patient without reference to the patient's own wishes (as many social theorists seem to believe them to be), but specifically as "an enabler" i.e. someone who enables the patient to fulfil his or her own desires despite biological or medical restrictions against them. Therefore if a professional nurse or carer were to act in the ways Smith, Szasz, and many other social theorists detail in their many harrowing examples, by not taking into account the preferences, desires or personal integrity of a disabled individual, they would not be acting in accordance with the requirements of their profession and would have "failed" at the job of being a nurse.[146] Thus, even for a person who is not "disabled" as per the definition in Chapter 1, but is merely experiencing pain or illness, a "nurse" who fails to take into account a person's autonomy and treats them simply as another object in their job schedule is simply a bad example of a nurse.

Thus, the cases that Swain and Smith note in which disabled individuals are treated as objects lacking desire, or are provided "services" which are totally unnecessary to their lives by councils or charities, do not seem to be (as usually argued), an argument against human assistance generally, but a case where the attitude of the assistant involved has utterly failed

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[144] As noted in Chapter 1, the differences between "disability" and "illness" are many and complex. Most social theorists however tend to criticize the "nursing" relationship, not specifically because of the use of the term "illness" in and of itself in this context, but because that use of illness automatically implies a person's dependence upon another for the fulfilment of their desires or the "fixing" of their body (see Davis for both), here, however, I am primarily concerned with the role of an assistant in the fulfilment of desires, rather than in the provision of "treatment for illness", since assessing to what extent a medical professional treating an illness is fulfilling a person's desires is (like the wider definition of illness itself), beyond the scope of what I am trying to achieve here.

[145] James Griffin, "Chapter 2".

[146] Michael Smith.

Also: Thomas Szasz.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

to take into account what their essential function is, namely providing for the fulfilment of a desire and ultimately the well-being of the recipient.[147]

To take a real world example, a person with quadriplegia may require the assistance of another person to dress themselves. The act of "dressing" however implies more than merely wearing clothes, it also implies a choice of what to wear, a choice of when to dress, and a choice of the most comfortable ways in which clothes may be put on. A nurse who turns up on a rota at a set time, pulls on whatever clothes are put out and brusquely leaves for the next appointment, is directly failing to fulfil the person with quadriplegia's desire to "get dressed" whatever he or she ends up wearing, just as if some inanimate device used by the person with quadriplegia such as a head tracker for his or her computer, a device which allows a quadriplegic person to operate a computer mouse by movements of the head, would be fulfilling its function only if it allowed the person with quadriplegia to fulfil his or her desire to access information and make full use of their computer when they desired, not merely when the device happened to be functioning according to its own erratic schedule, or only allow access to the specific parts of a computer's operating system the head tracker itself was compatible with (an area where assistive technology often fails in its requirements for access).

The second question, that related to power, therefore now becomes more clearly defined: does using a human assistant to fulfil a desire make the recipient who holds that desire automatically more powerless than someone fulfilling that desire on their own?

It is certainly true that when our desire depends upon another person, that other person has the "power" to fulfil or not fulfil the desire. Thus, when hiring a taxi to get to a particular destination, whether or not we reach that destination is entirely dependent upon the driver of the taxi rather than ourselves. There are, however, a number of factors which may influence the driver's willingness to fulfil or not fulfil our desire. Broadly these may be categorized as one of three forms of motivation. Some may be under our control, others not.

The first is the question of selfishness and reciprocity. We agree to pay the driver, then we have control over fulfilling one of her desires, i.e. the desire for money, in which case we are no longer powerless since now we each have a certain amount of control over the desires of the other person, and if one desire is not fulfilled, it is likely the other will not be either, for instance, we would not actually get to where we are going unless we agree to fulfil the driver's desire to be paid. Obviously relations between the two parties with desires and the situations may vary hugely throughout life, and there may be circumstances where either the recipient of the assistance or the assistant providing it has more power, for instance if the driver had a starving and dependent family and was desperate for any amount of money and thus would do far more to receive it, or if we were desperate to reach our destination and thus

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[147] Michael Smith.

Also: John Swain.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

would pay any price asked. Here, however, it is only necessary to note that so long as the two parties involved each have an ability to fulfil one of the other's desires, the power relation cannot be entirely that of suppliant and supplier.

The second reason is empathy. The driver may be a friend or family member, in which case she feels sympathetically towards our own well-being and therefore fulfilling our desire will (to a greater or lesser extent) be in accord with hers, and thus if our desire to travel were not fulfilled, neither would her desire to promote our well-being. This might be said to be the ideal case for having another person as a constituent part in the fulfilling of desires, since the extent that the empathetic person's "good" may be said to be that of the person they help is the extent to which the recipient may be said to have power over the assistant.

Catriona Mackenzie criticizes directly the idea of empathy in relation to disability, claiming that it is impossible to understand by a form of social empathy and "In each other's shoes" style thinking, what the experiences of another human (and in particular a disabled human), actually are.[148]

I will address her criticisms more completely in the conclusion, however for now it is worth noting that "empathy" here does not actually require understanding, rather it just requires the sort of assimilation of another's good, talked of by authors such as Edith Stein, i.e. the desire to promote the "good", or in this context the well-being of another human besides yourself, and in promoting that other person's "well-being" to fulfil at least partly some desire of your own.[149] The actual experiences and motivations for one individual to desire another's well-being might be varied and complex, however, for now it is just worth noting that such desires do in fact exist. From a parent going out of their way for their child, to a taxi driver who agrees to drop their customer on a more convenient side of the road, such promotions of the good of others are a part of human experience, and one which naturally any discussion of assistance must take into account.

Of course in reality, both of these first two factors, that of empathy and that of control over the assistant's desires, may exist concurrently, or more usually on a sliding scale. Even when engaged in the most standard commercial transaction, most people would not want to see the shopkeeper who sells an item or the worker who performs a service suffer significantly to do so, though it is doubtful many people would be willing to utterly forgo their desire entirely for the good of the worker or shopkeeper.

The third factor is the one that is most problematic for the fulfilment of desires. This might be called "external motivation", i.e. a case where the person who can fulfil the desire

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[148] Catriona Mackenzie et al, "Moral Imagination, Disability and Embodiment", *Journal of Applied Philosophy*, vol. 24, no. 4, (2007), pp 335-351.

[149] Edith Stein: *On the Problem of Empathy,* (Washington D.C: I.C.S. Publications, 3rd revised edition 1989).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

does or does not do so for some reason totally outside the control of the person having the desire. If the taxi driver will only drive us in a direction she is already going, or if she simply makes a point of driving or not driving for people with a certain physical appearance or characteristic, then we have no control over the situation at all and stand in a relation of powerlessness to the driver since her decision has been made with reference to some factor which we have no ability to change. Most obviously, this applies to cases of prejudice or direct discrimination, such as the bus drivers in America at the time of Martin Luther King who refused certain seats to, as they would put it, "Negros". Equally, however, this can apply to far less drastic instances, such as a shop assistant who refuses to serve customers because they have gone onto lunch break and are no longer officially working, or a restaurant which cannot serve a meal because they have run out of ingredients. In both cases, the shop assistant's job description or the restaurant's lack of ingredients, the customer with the desire can do little about either circumstance and is thus powerless, though it is worth noting that where this powerlessness is caused directly by the judgements or assumptions of the assistant, it is more likely to be felt as an injustice or a direct wrong than if it were simply the result of unlucky circumstance (a fact I will return to in Chapter 4).

As regards the question of disability and assistance, the crucial factor seems to be that whatever motivation the assistant has for the fulfilment of the disabled person's desire, it is not one which is outside the control of the disabled person with that desire, i.e. there are no pressures or motivations upon the assistant which remain external to the recipient.

This seems to be truly the problem which social theorists, like Swain, see in a disabled individual utilizing the assistance of another person, the problem of the powerless relation the disabled individual will be in if the motivations of that person are entirely outside the control of the disabled individual in question, such as the bad nurse and the person with quadriplegia noted above where the desire of the nurse is to adhere to some sort of professional or external code of behaviour or scheduled set of tasks and predetermined job requirements completely outside the control of the person with quadriplegia.[150]

Of course, there are cases where the provided assistance or desire fulfilment, even when the factors in control of it are outside the control of an individual, does fulfil that individual's desires. In disability, these may correspond to cases where governmental or other services, though reliant upon an externally imposed schema for their behaviour, do fulfil the desires of a disabled individual. Taking a "one size fits all" type of approach though, and assuming that such a plan, however well defined is indeed, as many social theorists have noted, opening the door both to the relations of powerlessness, and the possibility that such a system will fail in accomplishing whatever desire fulfilment it is assumed to work on. It is for this reason that Michael Smith notes that the Direct Payment system whereby disabled individuals, instead of receiving governmentally provided services worked out on a basis of what the service provider deems necessary, receive a quantity of money to pay for and

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[150] Ibid.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

arrange such services themselves either privately or through agencies, has had so much success.[151]

So, to be effective, a human assistant must, A: actually fulfil the desire of the person involved and, B: either through empathy or through a factor, such as payment, be in a position where their own desires are in conjunction with those of the disabled recipient, (I will return to the question of the assistant's attitude in Chapter 4).

Of course there are arguments that disabled individuals should as moral beings strive to perform all their desires without the aid of any human assistant at all, simply because the acceptance of assistance, even when an assistant is not overpowering the patient with assisted desires, is itself an act that denigrates the patient's dignity. Indeed, in some philosophies (notably that of Aristotle), the ideal of a human is a person who, like a super hero, has the desire and ability to aid others, without at the same time ever needing aid themselves.

The problem, however, with this idea is that such super heroes exist only in films and comics. Truly, the only way to escape all human relations would be to really live alone on a desert island and interact with nobody else, since even in the most mutually respectful and cordial of friendships, one person will at some time fulfil the desires of another, even if these are such simple desires as the company of another individual or a desire for a shared activity. For instance, if my friend and I both desire to converse and are interested in each other's conversation, then we obviously stand in a relation of fulfilling one another's desires. It is, however, part of being friends, that our desires are intermingled, and as I fulfil my friend's desires, he will fulfil mine and vice versa. To claim such basic human exchanges as "undignified" or try and locate a subordinate agent/patient type of relation in all these sorts of human interactions would seem to be near impossible.

Turning to disability specifically, if then we hold that disability is a pervasive and nearly universal state which simply occurs in different degrees, then the interactions of disabled recipient and assistant would seem just as pervasive and nearly all consuming as other sorts of interactions, such as commercial ones. It is, however, completely true that just as we need rules of conduct for commercial transactions precisely so that relations of powerlessness do not occur, so then the relationship between the disabled individual and their assistant must be subject to similar regulation and examination, so that cases of "bad assistants" can be categorized as the immoral acts they actually are, based on how they stand within the assistance relationship and how it should function for the good of both the disabled recipient and indeed to an extent their assistant.

Thus far we have assumed only that a human assistant is essentially the same as a mechanistic device, i.e. something which fulfils any desires of a disabled person that they are biologically precluded from fulfilling, for example, a person pushing a wheelchair satisfying a person with paraplegia's desire to travel somewhere being functionally equivalent to a

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[151] Michael Smith.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

wheelchair motor. This, however, fails to take into account the most key thing about human assistants; namely that they are humans, with desires, attitudes and well-being of their own. A disabled person making use of a human assistant to fulfil desires is not simply in the position of giving orders, as one might to a programmed voice assistant function of a mobile phone, but standing in a complex set of social and moral relationships to the other person, and as such human assistance, even when the desires of individuals are entirely reconcilable, has some rather unique problems surrounding it.

The first is competence. Even when fulfilling the desires of a disabled person is the mutual goal of the recipient and their assistant, the assistant may or may not be competent to fulfil such a desire. This may occur with professional assistance, but is more likely to occur with friends, family members or strangers. Certainly I myself have occasionally asked a person for directions, only to receive the wrong information, or information in an entirely unusable form. On one occasion I remember being told for example when walking up a street, "Take the fourth exit at the roundabout", as though I were driving a car. In the case of family members or professionals of course, it may be possible for them to acquire competence through repeated experience of fulfilling similar desires and familiarity with the recipient, but this may not be the case with strangers, or with certain professionals who change on a regular basis. Furthermore, whether a person does or does not learn such competencies depends very much on, A: the assistant's ability to learn generally, and B: the disabled recipient's ability to articulate when a desire is or is not being met.[152]

Then, there is the question of arrangement. A tool or aid is inanimate and obviously will be predictable in where and when it becomes available and its mode of operation, indeed if it is unpredictable or inconsistent in its operation we would say that it is "a bad aid" and probably not make use of it. This is doubly true for a disabled individual who may be reliant upon that inanimate aid to fulfil some very basic desire, such as a person with paraplegia's need for a stair lift to get up stairs to the bathroom, and the intensive inconvenience caused if that lift should fail. This is not true of human assistants, who, as people with lives of their own, obviously work on their own schedule. Indeed, there are cases where a disabled

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[152] It is for reason of lack of communication that often people with learning disabilities have a characteristic file written by a family member or other responsible person which is supposedly passed on to anyone trusted with their personal care, which details their habits, likes and dislikes, as well as their physical needs which they may not be able to articulate themselves. Of course, there is a risk that this file may be incorrect, or still worse that the reader of the file is unable to interpret what communications the person with learning disabilities can give, and simply follows the file instructions or other information mechanically.

On the other hand, it may also be true that there is vital information that the learning disabled person simply cannot communicate, for instance dosage of a needed medicine, and thus it must be communicated by a responsible third party in order that the assistant is aware of it. This would seem to be a clear case where treating a learning disabled person morally as a child, as noted in Chapter 2, may be justified, and provides an extremely good answer to the problem of how we both value and encourage a person with learning disability's autonomy, and yet at the same time ensure that their physical well-being and care are maintained over and above the limitations of their mental abilities.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

individual must wait a significant time to receive assistance from a human, or must book an "accessible" service long in advance. For example, Nottingham has a dedicated taxi service free to disabled customers, however in order to use this service, bookings must be made three weeks prior to use. This means a service which purports to give disabled individuals the same access to the social world as an able bodied person would receive through driving a car, fails entirely since most able bodied people do not need to book their car three weeks in advance before driving. This, however, is not due to a malfunction of the cars the taxi service uses, but simply the demand upon the service, and their number of drivers, both unfortunately factors outside the disabled recipient's control, albeit factors there is little way of changing on an individual level.

Then, there is the problem of consideration. If in fact a disabled person is a moral being themselves, they will naturally not wish to consider a person as simply a means to fulfilling a desire, particularly if the person is a friend, family member, or indeed (if the disabled individual has a developed sense of ethics), a perfect stranger. Thus, in dealing with that person in the context of assistance, the disabled person must constantly be considerate of their desires, well-being and attitude, things which would not affect the disabled person in relating simply to a tool or device. For instance, a disabled person may feel a sense of guilt when a paid assistant is performing some task, still more when the assistant is unpaid, even when this task is indeed one which the disabled individual could not fulfil themselves, or fulfil only with intensive effort, indeed a disabled individual might feel beholden to perform some task with the accompanying intensive effort simply to avoid having a non-disabled assistant do it for them. This certainly makes the task of using assistance of any kind to fulfil desires more difficult for a disabled person, and is one aspect of experiencing life with a disability often not covered by theorists in the social model, indeed some, like Smith, go as far as stating that a disabled person has a direct right to the assistance of others and should repress feelings of guilt.[153]

Corresponding to this, there is the attitude of the assistant themselves, and how such an attitude affects the disabled recipient. If, for instance, (as Swain notes) a disabled person is constantly being made aware of how much trouble the assistant is required to go through to fulfil their desires, it is doubtful that such an assistant actually contributes to their well-being at all since the intensive feelings of guilt and negativity could negate any benefits to a disabled person's well-being that having the assistant aid in fulfilling their desires produced.[154]

By contrast, in Botswana anthropologists noted that disabled people were perceived by many in society as heroic figures who had a right by their own status to receive

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[153] Michael Smith

[154] John Swain.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

consideration from others.[155] Though such attitudes in an assistant are often still uncomfortable for the disabled person in terms of moral relations, it is far better than cases where the disabled person is made to feel a helpless burden upon an assistant, (a topic I will explore further in the next chapter).

Finally, there is the disabled person's own desire for autonomy. A disabled person may choose to fulfil their own desires without the aid of another person simply because they, A: have a desire for autonomy which receiving the aid of another would not satisfy, or, B: consider the fact that they and not another person actually fulfil the desire of paramount importance in its fulfilment. I will discuss the second of these qualities in the next section when I turn to the alteration of desires themselves rather than the means by which they may be fulfilled.

For all of these reasons however, a human assistant, though able to either aid in the direct fulfilment of a disabled person's desires, or reduce their effort costs by a substantial margin, even when the question of power is no longer an issue, should not be considered as the ultimate solution to the fulfilment of a disabled person's desires. Where attitude and desire for autonomy are considered, a disabled person's desires may simply not be fulfilled by using a human assistant, and even in other cases, requirements to adhere to the assistant's own schedule, or risk the assistant not being competent both mean that using an assistant is not as effortless as it appears.

Before considering whether in any situation a human assistant actually does the job of fulfilling a disabled person's desires, we should ask the following questions:

Does the disabled individual have an ability to influence the assistant's behaviour in the fulfilment of a desire?

Is the assistant capable of fulfilling that desire?

Is the assistant able to fulfil the desire on a schedule which suits the disabled person?

Does utilizing an assistant interfere with the disabled person's well-being in terms of autonomy?

Are the feelings of the disabled person, and indeed of the assistant, such that fulfilling the desire by way of assistance will be beneficial to the disabled individual's well-being?

Only if the answers to all of these questions, in any given situation, can be positive does it seem fair to state that the assistant has fulfilled the same function as a device, namely

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[155]BenedicteIngstad, "Mpho yaModimo - A Gift From God: Perspectives on "Attitudes" Towards Disabled Persons", *Disability and Culture,* ed. BenedicteIngstad, and Susan Reynolds Whyte, (London: University of California Press, 1995), pp 246-266.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

intervened in the life of a disabled person such that a desire which may either require exhaustive effort on their part, or which may be impossible to fulfil, has in fact been fulfilled.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section C: Animal assistants.

In the previous section I have addressed only the idea of specifically human assistants, just as in Section A I only discussed inanimate aids and environmental adaptations. One other form of assistant, however, which is available to certain groups of disabled people to aid in desire fulfilment, is that of assistant animals. Though service dogs (especially guide dogs), are most common, the category of assistance animals also includes: physical assistance or "helper dogs" for those whose motor impairments prove difficult in household tasks; alert dogs for people with impaired hearing to notify them of noises in the environment; and so called "Pat dogs" or "Buddy dogs", who provide companionship for those with conditions such as depression or chronic anxiety. Neither are all service animals dogs, since guide horses are well known, (particularly in heavily rural areas of the world), and other assistance animals such as monkeys, dolphins and even birds exist. Though since I am mostly personally acquainted with assistance dogs (particularly my guide dog Reever), I will confine my examples here to predominantly canine ones, although it is hoped the discussion in this section, being mostly concerned with the relationship between animal assistant and human recipient rather than the specific nature of the animal in question, may also apply to other species as well.

In the context of this chapter's discussion on accessibility, service animals seem to possess both some of the characteristics of a human assistant, and some of the characteristics of an access aid.

On the one hand, my guide dog Reever does certainly aid in the fulfilment of my desire to travel safely, and it cannot be denied that her efforts reduced markedly the effort costs implicit in my undertaking any journey, indeed this was my major experience when I started walking with her as opposed to walking using only a white cane for mobility purposes, that I was no longer required to concentrate intensively on every tiny aspect of the environment to avoid injuring myself on obstacles or losing my way.

It is also true that from the standpoint of fulfilling desires autonomously, an assistance animal's status as an animal over which a person has stewardship (a metaphor borrowed from Mary Warnock), means that often a person can still feel that a desire is being fulfilled independently of others.[156,157]

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[156] The notion of animals as property and their status related to humans is a large and complex one. However, here it is only necessary to note that a person is "responsible" for their animal assistant, and that this responsibility communicates itself as a felt sense of autonomy. Mary Warnock uses the term "Stewardship" to describe human's relationship to animals, i.e. a human has authority over an animal, but authority tempered by the needs to protect and conserve rather than just to dictate. Whether Warnock's metaphor of Stewardship is appropriate for that of all animal relations to humans it not a matter I will consider here, but it does seem apt as a description of the relation a disabled person bears to his/her animal assistant.

[157] Mary Warnock.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

This is by contrast to the fulfilment of a desire by a human assistant where the disabled person may feel that they are intrinsically dependent upon another human, and that this dependence negates the satisfaction felt at freely fulfilling the desire themselves. This is not to say that a person's relationship to an assistance animal is entirely that of owner and disposable property, however, due to intrinsic species differences it is one where the person remains primarily in charge of the motivation in the relationship, and the animal assistant responds to that motivation, e.g. if a physically impaired person asks their dog to pick up a dropped object and bring it to them, it is the disabled person, not the dog who makes the overriding decision to pick the object up, where the dog, it is hoped, is pleased to do so.

Also, as with the use of access aids, an assistance animal, being that part of its definition as an assistance animal is to provide that assistance, does not bear some of the loaded emotional problems of interacting with a human assistant associated with guilt or morality. I do not need to be concerned, for instance, if Reever wishes to go out for a walk at the same time I do, or worry that Reever might perceive me as dependent due to me requiring her assistance for mobility.

That being said, one other less fortunate aspect of the ways in which assistance animals resemble access aids, is that the access they provide is in some way incomplete, i.e. they can rarely if ever give a disabled person the same experience of desire fulfilment as an able bodied person in a similar situation. Though Reever is quite capable of finding her way around obstacles and recognizing generalized categories of objects such as "stairs" or "door" which she can then find and direct me to, she could not read a sign, get directions from a map or recognize an unknown place instantly, such as a shop. Indeed while she can quite easily "Find a bus stop" she is certainly not able to tell whether it is the right bus stop, or to know which bus I should board once there.

There is, however, one very important aspect in which animal assistants differ markedly from inanimate adaptations, namely that as animals they can be involved in a relationship with the recipient of their assistance. Indeed, for many service animals involved with mental illness, it is this relationship which is central to their fulfilment of their function as assistants i.e. providing comfort, stress relief or companionship.

Even for assistance animals like Reever, whose chief function is mainly the very practical fulfilment of common place desires such as mobility, it is unquestionably the relationship with their person which is central to their ability to provide assistance. This is both because (as I was told during my own guide dog training with Reever), an animal such as a dog's chief reason for performing an activity, such as guiding or assistance in lifting objects, is indeed to please the person whom they relate to, and because, manifestly, the closer the relationship with a service animal, the more the service animal will be willing to do in service of that relationship.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Indeed, while I do not know if dogs are capable of empathy in the literal sense, it is certainly true that dogs, and likely some other service animals, are able to put the good of their person before their own, or at least, be conscious of what the person sees as good or bad, though Reever's ability to reason and be aware that I will be injured if her guiding is incorrect has sometimes surprised me, especially when it revolves around her realizing when not to obey an instruction, for example if I urge Reever forward but there is an obstacle in the way I cannot see. This indeed is why those who believe that animals are simply mechanistic and that dogs particularly can obey implicitly on a gross reward/punishment model are directly incorrect, indeed during my training I was told sternly not to harbour any such beliefs at all and rely on rewards such as treats just as a reinforcement, not as an end in themselves.[158]

Much of the training service animals and their respective people receive directly promotes the relationship between the service animal and their person, so that when it comes to a choice between the service animal providing assistance or satisfying their own desires, the animal will be more inclined to choose to act on behalf of their person rather than for their own satisfaction. To take one specific instance, Reever had to learn when walking with me that running in the direction of any other dog on the street was not a good idea despite her inclination to do so. Conversely, during training it is also necessary for the person to actively form an attachment with the animal, and take on a role of stewardship, i.e. caring for the animal, and indeed frequently considering the animal's interests, especially in situations where the animal is affected by the human environment, for example providing food, protection from things like traffic, opportunities to play and have pleasant experiences, etc.. This is why I appreciate the "stewardship" metaphor, since it implies not only ownership, but also a sense of responsibility or caretaking, which are undoubtedly central aspects of the relationship with an animal assistant.

It is also undeniably true that the relationship a disabled person has with their service animal, can itself become a deeply loving and close one, and one which, quite aside from the utilitarian fulfilment of desires, can provide a huge benefit to the disabled person's life and well-being, especially if the disability, like visual impairments, also makes communication with others difficult.

It must also be remembered however, that the relationship a person has with an assistance animal does entail its own set of responsibilities and compromises, indeed it is frequently necessary for a disabled person with an assistance animal to consider the animal's good first rather than their own, and to heavily alter their life or circumstances around their animal assistant's needs.

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[158] This is why I categorically disagree with those who flatly disbelieve in the ability of animals to reason or make value judgements, given that I risk literal physical harm on a daily basis on that ability.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

These difficulties can also bring their own social requirements, for example, discussions about whether service animals are allowed in places like restaurants, and where a dog or other animal might relieve themselves, as well as more general responses from others, (something I will return to in the next chapter).

It is these requirements and necessary life alterations, and the effort implicit in meeting them which mean a service animal is not ideal for every disabled person despite the fact that on average the fulfilment of a desire by use of an assistance animal is generally preferable to going without it (were it not the case, the intensive training and inconvenience would make the very idea of an assistant animal superfluous). An animal does not fulfil the role of a human assistant entirely, nor can they provide complete access or reduce the effort costs in desire fulfilment to such a level as to negate the person's disability, though certainly they are a very unique way for a disabled person to fulfil desires and form a complex relationship as well, particularly since animals, unlike any current form of technology we have, have some ability to reason and form emotional attachments, thus the scope of their ability to fulfil desires is potentially far wider than inanimate objects, albeit, as stated earlier, the effort costs in becoming steward to an animal do always need to be considered carefully for each individual, i.e. they're not right for everyone.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section D: Altering the conditions of desire fulfilment

Thus far in discussing the desires of disabled individuals, we have only considered their fulfilment from a comparatively narrow angle, namely that a person's desires are only fulfilled when a state of affairs occurs that initially matches their intention. While a useful schema for discussing the biological limitations implicit in disability, desire fulfilment is a far more complex matter and one which ethicists and theologians have discussed for nearly two thousand years.

In the context of the current discussion, one particular aspect of fulfilment of desires, which thus far we have neglected, is the interplay between the initial intentions or beliefs of an individual, and the circumstances under which their desires may be fulfilled. More specifically, we have not yet discussed cases in which the conditions for the satisfaction of a desire may be altered to allow it to be satisfied in the face of opposition.

Suppose for instance, Jo has the desire to fly an aircraft, but suffers from a heart condition that would cause a severe risk of death were he to ever actually fly off the ground. Since it would seem to be implicit in the idea of flying an aircraft that one leave the ground, it would seem that Jo's desire is unfulfillable and therefore a source of pain. If, however, Jo altered his desire to simply having the sensory experience of flying a plane, it would seem that the ability to use one of the grounded plane simulators upon which pilots train, which simulate all the movements of an aircraft in flight via the use of hydraulics, would be a possible variant of the desire which Jo could fulfil irrespective of the condition that prohibited him from the fulfilment of his initial desire. Obviously, there would be many circumstances surrounding his initial desire to fly a plane that Jo would need to forgo in the alteration of his desire to simply having the experience of flying a plane, rather than actually doing so. He would, for instance, have to give up any hope of having a career as a pilot and transporting himself from country to country by plane, nevertheless, the desire to "experience" flying a plane without having to do so upon a simulator would be achievable given Jo's biological limitations, whereas the desire to actually work as a pilot would not be, and so there would be an advantage to Jo in altering his desire.

This sort of compensation occurs in the lives of disabled people constantly, the realization that through sheer limitation, or even an unreasonable amount of required effort or fatigue, an unfulfillable desire might have to be changed to one which only related to the initial desire, rather than was identical with it. Of course, this relation is not a simple one. As many commentators on desire have argued, there is considerable debate as to whether any given object is desired because it is in itself of value, or valued simply because it is desired by an individual.[159] For instance, if Jo's valuing becoming a pilot of an aeroplane conferred

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[159] L.W. Sumner, "Something in Between", *Well-being and Morality: Essays in Honour of James Griffin*, ed. Roger Crisp and Brad Hooker, (Oxford, Clarenden Press, 2000), pp 1-19.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

value upon it directly, the simulator option might be best thought of as a "partial" fulfilment of his desire, so it fulfils only some of the requirements set by his initial desire, but this is better than none.

If, however, Jo desires to fly an aeroplane for some other, more layered reasons, because he thinks pilots gain great status, because he wants to travel and see the world, or indeed because he wants a certain experience such as that of seeing the world from above through a window, then the simulator option, rather than being a partial fulfilment of his desire, i.e. a poor quality, second class option to which he must resign himself, would rather be said to contain "some" of what he wants rather than the "all" provided by his initial desire to be a pilot, though another desire wholly unrelated to the circumstances of flying a plane might do so equally well or better. For instance becoming captain of an ocean liner might fulfil Jo's desires for travel and status far more readily than the simulator option would.

There seem in the case of desires and disability fairly plausible reasons for assuming both of these positions are true, or at least that both may hold merit in different circumstances, since if we asked Jo why he wanted to fly a plane, he'd probably list a number of beneficial and understandable characteristics rather than just, "because I want to". On the other hand, however, it would seem that an experience closer to Jo's initial desire, i.e. the simulator, would be more likely to bring him a sense of well-being and overall satisfaction simply because it is related to the desire he holds that is precluded to him, rather than being an unrelated desire which might happen to tick some of the same boxes. Indeed Havi Carel defines disability in its interaction with well-being as a positive experience of learning how not to have certain desires fulfilled.[160]

Whatever the exact relation between the person who desires, the objects of original, biologically restricted desire, and a possible new, non-restricted desire, it does seem that the key process here is a relation of similarity. If, for instance, someone suggested to Jo that he become a taxi driver instead of a pilot, that would not be a reasonable suggestion, since the experience, mode of life, and just about everything else that distinguishes the two states of affairs (being a taxi driver and being a pilot), are entirely and completely different, making such a suggestion less than reasonable. Yet, it is also true that the lives of people with disabilities, especially those with sensory or motor impairments are full of just those sorts of suggestions. Someone (more often than not someone who does not suffer the same disability), will substitute an unrelated desire which seems to have little or no similarity to the

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Also: John Broome, "Incommensurable Values", *Well-being and Morality: Essays in Honour of James Griffin*, ed. Roger Crisp and Brad Hooker, (Oxford, Clarenden Press, 2000), pp 21-38.

Also: Peter Railton, "Taste and Value", *Well-being and Morality: Essays in Honour of James Griffin*, ed. Roger Crisp and Brad Hooker, (Oxford: Clarenden Press, 2000) pp 53-74.

[160]HaviCarel, "Chapter 2".

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

original, biologically restricted object of a disabled person's desire (or at least an object of desire which the one who makes the substitution assumes to be biologically precluded).

For example, on one occasion I was asked by the musical director to perform in a light opera production in Buxton Opera House since the chorus needed extra tenors. While the musical director was keen to have me sing, the stage director himself was absolutely against the idea of having a visually impaired person on stage. He clearly believed that the act of performing on stage was biologically prohibited due to my possession of a visual impairment. The director did however suggest that I stand in the wings, not appearing on stage or participating in the production, and sing from there. Of course, a critical factor here is that of the source of the restriction. In my case, it was not a direct biological limitation that prevented me from performing on stage (I'd done so several times before), it was the assumption regarding the biological limitations of visual impairments made by that director, an assumption which was in actuality false, but which he refused to alter even upon receiving information to the contrary. However, even had his assumption been true, his proposed solution, that I stand in the wings, effectively out of the production, and simply sing privately, was so unrelated to my initial desire to perform on stage as to be entirely unreasonable.

Thus, disturbingly often in the lives of disabled people, what alternative desire is proposed to take the place of a supposedly restricted desire, and indeed whether a certain desire is restricted at all, seem to be matters decided not by the disabled individual themselves (the one whom we should assume in the vast majority of circumstances is in the best position to pass judgements over their own desires and capabilities), but by people or institutions within society itself entirely unrelated to that disabled individual.

These sorts of social restrictions are often deprecated by those working in the social model and quite rightly so (Darke, Shakespeare, Silvers, Wasserman, Davis, and virtually every other social model commentator deals with this point to some degree or other).[161] Indeed Szasz and Tassano attack the entire medical profession on these grounds claiming that doctors have a vested economic and political interest in remaining in control of the desires of people who are ill in order to maintain their power in society.[162] Whether indeed this idea, that a person other than the disabled, autonomous adult is in some way more qualified to

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[161] Paul Darke.

Also: Tom Shakespeare.

Also: Anita Silvers.

Also: David Wasserman et al, "Disability: Definitions, Models, Experience", *Stanford Encyclopaedia of Philosophy,* ed. Edward N. Zalta, (Summer 2016 edition).

Also: N. Ann Davis.

[162]Thomas Szasz;Fabian Tassano.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

judge both the biological restrictions of any disability and what desires may be reasonably substituted for restricted ones is deliberate, or at least is motivated by less than savoury moral grounds or not, is a question I'll further discuss in the next chapter. Whatever the motive however, it is certainly fairly obvious that such assumptions, reassignments of a person's desires and downright obstructions, do exist. A disabled person might frequently be told that such a desire is "not possible" just because a certain third party thinks it is not, or fobbed off with some low grade alternative to his or her desire which bears little to no relation with its original object, but which the person making the decision believes is more "appropriate".

It seems therefore critical that if a theory of disability is to deal with the idea that desires are biologically precluded, we must give an account of some way of measuring, A: when a desire is or is not biologically precluded by a disability and, B: how we may decide when any proposed alternative does or does not bear a reasonable relation to the original desire.

The first and most obvious answer, is that in determining these two factors, the disabled individual themselves has far more experience, weight and power than anyone else, simply because it is their desires that are most affected by their own physical and psychological state and therefore they are in the single best position to determine whether or not any given desire requires modification or an alternative proposition.

Thus, while it may be universally true that a given activity, say catching a train as detailed in the example in Chapter 1, will be naturally more difficult for people with certain categories of biological limitations, for example people with paraplegia, visually impaired people, etc., whether any given disabled person will decide to catch a train or for instance use a taxi will depend upon more general circumstances surrounding that person's life, how much time he or she has for the journey, how much energy he or she has after the journey, etc.. Thus, while we can say on a general level that catching a train for a person with a disability is more difficult based on the averages and the castaway example, whether any specific disabled individual should or should not catch a train is a matter best left up to themselves.

Of course, this sort of thinking is only possible if, as detailed in Section A, disability is thought of not as an absolute category of persons akin to nationality or gender, but as a relational, qualitative category which affects a person's freedom of action and ability to carry out desires similarly to the category of "being lost" and is therefore a state into which people may all fall at one point or other throughout life.

The admission of the autonomy of a disabled individual, though trivially true does seem to need a more formal statement, since in the lives of disabled people denial of autonomy occurs frequently, indeed I myself recall one disability professional telling me flat out, "Disabled people are not the best judges of what they can and cannot do". Of course, it is true that there are cases where a disabled person simply is not aware of possible risks to others or themselves in possessing a certain desire, or is not aware of how their own disabled

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

status has an effect upon their desires. In these types of cases, however, if we understand disability as to be a state that everyone falls into at some point or another, it would seem that the disabled individual here, in misunderstanding his or her own desires, is guilty not of a misunderstanding regarding the status of "being disabled", but simply of a misunderstanding in connection with their self and their desires. This is something whose cure is self-knowledge, access to information and experience, rather than the tyrannical impositions of an external agency.

So, for instance, a person with quadriplegia might firmly believe that using a computer is not an optional desire and that they should abandon all desires connected with it, because they are not aware of adaptive aids such as head and eye trackers. Such aids would allow them to use a computer with, if not exactly the same effort as a person with normal motility, certainly far less than would be needed without them. If we therefore assume that the disabled individual themselves (when acting competently as I will expand upon in the next chapter), is the best measure of whether a given desire is or is not biologically restricted, it seems then that the measure of when an alternative proposed desire is reasonably related to the restricted one is also the disabled individual themselves, and that in proposing such alternatives, those who are unreasonable are guilty of not taking into account the feelings of a disabled person, and thus behaving in an unethical manner.

Just as British colonial doctors in places such as Ceylon, who insisted on "civilizing" the natives of the colonies they were involved with by enforcing alternative practices such as medically assisted births (in the case of Ceylon), and were guilty of not considering the feelings and interests of the native population, so a person who proposes an alternative related desire to a disabled individual which is not in that individual's best interest, such as the above mentioned director, is guilty of unethical, and high-handed behaviour.[163]

It may also be seen that this proposal of alternative desires and exploration of alternatives to precluded desires is one of the chief responsibilities of a good, rather than bad, assistant to a disabled person, as in fact is detailed by Michael Smith.[164,165]

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[163] Margaret Jones, "Infant and Maternal Health Services in Ceylon, 1900-1948: Imperialism or Welfare?", *Social History of Medicine,* vol. 15, no. 2, (August 2002), pp 263-289.

[164] Michael Smith.

[165] Smith details the case of a boy, Tony, with Down's syndrome. Though Tony does not have the mental equipment to fully control and plan his life, Smith details how, with the aid of an assistant and the direct payment programme, Tony can make choices about desire alternatives and what "he" wants to do from day to day. This is a practical example of the treatment of a disabled individual with unconscious, mental impairments as a child. Just as a good parent would wish his or her child to experience the pleasure of choice and fulfilled desires to as great an extent as possible, but not to an extent where the child would harm themselves, so Tony's carer allowed him to take pleasure in the choices and ordering of desires which he is able to, without risking his reduced responsibility causing injury to himself. This also shows that Tony's carer is working in Tony's best interests to as large an extent as possible, since, as John Stewart Mill argued, disallowing someone freedom of choice would ultimately go against their best interests.

Of course, there are some cases in which a disability (particularly those such as depression or schizophrenia), may create desires which an individual may not wish to fulfil, such as a person with Depression having a temporary desire to commit suicide, however it would seem that again this is a case where self-knowledge and knowledge of the person's own status and condition is needed, and especially knowledge of what desires may be caused by that condition as opposed to those autonomously accepted by an individual in the normal course of their life. Indeed often people living with such conditions (especially ones, such as bipolar disorder, which run in episodes), use the consistency of desires as a guide to the effective scope of their condition. This form of self-knowledge also ties in to the idea of competency which I will discuss further in the next chapter.

So, we can say that the preclusion of a biological desire is a fact determined by an individual's current relation to his or her state of disability, and his or her competence working within that state, and that the proposal of alternative desires is only a viable option if it is undertaken in the spirit of promoting the interests of the disabled individual themselves, rather than the interests of the individual proposing the alternative desires.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section E: Conclusion

In this chapter we have examined the relation between disability and desire. We have established how, and in what ways, the circumstances surrounding the effort made to fulfil a desire may be altered, either by external changes to the world and environment, or by the intervention of a human assistant whose desires are synonymous with those of the disabled individual they are assisting. We have also discussed the relationship of an animal assistant to a disabled person, the unique compromises and benefits of such a relationship, and the responsibility of stewardship it involves, (noting that such as a relationship, though beneficial is not for everyone). We have also suggested that in cases where accommodations to fulfil desires cannot be made, a disabled individual, or a party attempting to work in their best interest, may propose an alternative desire, whose relation to the initially restricted desire is also a matter the disabled individual themselves needs to determine. As noted, however, this puts huge amounts of power of choice into the hands of the disabled individual themselves, and also depends upon the attitudes of those around them, both in an immediate context, and more generally throughout society.

Therefore, in the next chapter, even though we take disability to be the biological restriction detailed in Chapter 1, it will be necessary to analyze the ethical relations and responsibilities of both individuals experiencing a state of disability, and those they interact with, in order that the definition detailed in Chapter 1 is able to achieve an ethically harmonious state both for disabled people and those surrounding them. Since, as a state which affects all humans to a greater or lesser extent throughout life, disability is, like other ethical states, such as family relations or community responsibilities, one that is implicit I believe, with both moral push, and moral pull, i.e. a disabled person is not merely the bearer of relations to others such as assistants (human or animal), friends, family and even strangers, but also bears some implicit responsibilities inherent upon them due to existing in a state of disability towards the world and their ability to fulfil desires within it.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Chapter 4: Disability and relations to the non-disabled

Introduction

Disability is, as we have established, more than just a social phenomenon, being a relation between a person's biological and psychological self, the environment in which they exist, and their desires and how those desires might be fulfilled. This contrasts with many theories of disability which implicitly state that disability is directly constituted in how disabled people are perceived and categorized by those around them.[166] Nevertheless, as shown by the discussion in Chapter 3, and indeed by the impetus behind the formulation of the social model in the first place, the interactions between a person's own disabled state and how that state is directly perceived by those around them play a huge part in a disabled person's ability to fulfil his or her desires, from a desire for a certain career or path in life, to desires attached to the mundane but vital details of everyday living such as travel, dressing, eating, and of course relationships with friends, strangers and family. Though, as shown in the first chapter, disability is not just made up of these social relations and perceptions, not the least because under the definition I have proposed disability is a far wider category than the usually labelled groups, e.g. "the blind", or "the physically impaired", yet no discussion of a definition of disability would be complete without addressing them.

In the previous chapter, we noted that disability is a state similar to "being lost" in its placement of a disabled person in a negative relationship to their environment. Though "being lost" is itself not implicitly a social state, society can have a huge impact on a lost person. People's willingness to help, society's shaping of the environment in terms of maps and street signs, even the relative language spoken by the lost person and those around them, not to mention the attitude (helpful or otherwise) of any people the lost person asks for assistance. Equally, however, the lost person is not merely a passive sufferer of a misfortune. Logical exploration of the environment and use of orienteering skills, a sympathetic attitude if asking for directions, and the ability to explain the lost person's exact problem in detail when conversing with locals will all be helpful skills which someone who is lost could develop and use, both to alleviate their immediate unfortunate circumstances, and as useful skills to be perfected should the lost person (as seems entirely probable) become lost in the future. We might say therefore, that a person prone to being lost is advised to become "competent" in coping with their state of being lost.

As part of this set of competencies which a person may develop, one major aspect seems to be the need to treat others, even when requesting their assistance, with respect and consideration. Imagine the stereotypical, colonial era English tourist, who, when lost in a foreign country, becomes short tempered, aggressive and abrasive, often behaving rudely

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[166] David Wasserman.

Also: Sara Goering.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

towards locals even when asking for assistance, such as by speaking slowly and insultingly, without trying to learn any local language or geography, or wilfully misunderstanding attempts by locals to communicate with them.[167] Such a tourist simply expected locals to accommodate them "because they're English".

We would class such a tourist as not only boorish, ignorant and possibly even immoral, but also more fundamentally, as "incompetent" at dealing with the matter of being lost in a foreign country, an incompetence fuelled by their social prejudices and beliefs about their own status and that of the locals they encounter.

Equally, however, though existing in a negative state related only to their own circumstances, all the moral responsibility for dealing with the unfortunate condition of their life does not rest just with the lost person. If those in a lost person's environment, even when approached in a considerate manner, respond with disdain, wilful ignorance, mockery, derision or even attempts to take advantage of the lost individual, then they would be just as guilty of behaving immorally as the tourist mentioned above.

Thus, "being lost" is both a situation which has a distinct level of competency expected of the person who is lost, and also a necessary moral requirement upon those around the lost person by virtue of his or her misfortune, even more especially if the lost person's desire to alleviate his or her state of being lost is being assisted directly with reference to the desires of those around them, say by the lost person employing a guide, or having a local friend who knows the area. In ethical terms therefore, we could say that the situation has both moral push, i.e. the implicit moral imperative upon locals to assist a lost person caused by that lost person's reduced circumstances in that environment and to provide that assistance in such a way as to not be in itself offensive or unpleasant, and moral pull, i.e. a lost person's requirement not to treat those who can possibly provide assistance in an unethical fashion, both when requesting assistance and when interacting with an assistant, as Kant would say, treating people as ends in themselves rather than as means.

It is my belief that the social relations surrounding disability, despite the comments by social theorists such as Wasserman, Swain and Darke who categorize disability's social relations only in terms of a natural assertion of denied moral rights, are just as reciprocal in nature as those I have outlined above regarding "being lost".[168] While there is undoubtedly a

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[167] In his autobiography, *Going Solo*, Roald Dahl gives a perfect example of such colonial era tourists on his journey to South Africa. It is not merely the colonial era tourist whom we may look to for an example of an individual incompetently dealing with a negative state, though since the negativity of "being lost" is so profound and the completeness of a foreign country as an environment is so all encompassing, the tourist perhaps provides a highly complete example and one which obviously closely parallels the state of a disabled person. People who become unpleasant when getting the wrong meal in a restaurant or the wrong item in the post, or those who angrily demand of the police, "What are you doing about it?" when they have been the victims of a crime may also be thought of as exemplifying this incompetency at dealing with misfortune.

[168] David Wasserman.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

definite moral imperative for the non-disabled members of society to alleviate, rather than exacerbate the negative consequences of disability, a disabled individual also bears moral responsibility for learning to live with their negative circumstances in as competent and efficient a way as possible. This involves taking into account the needs and desires of those around them, including human assistants, as well as learning practically what is specifically best for the fulfilment of their desires with respect to their own individual circumstances, what forms of access aids or adaptations might be available to help with desire fulfilment, and practicing to be either a "good steward" if deciding to use animal assistance, or a "good partner" if being the recipient of human assistance. This idea seems even more necessary if we categorize disability as a general, biologically inhibitive state which will be experienced by most people at some point in their lives, rather than as only applying to some specialized groups within society who have specific cultural or political interests which need exceptional treatment or recognition. Thus, in this chapter I will attempt to present a reciprocal view of the social relations of disability, whereby the necessary moral attitudes of those around a person with disability are balanced by a similar set of moral duties implicit upon a disabled individual, and any discussion of disability access, advocacy or social equality must recognize both sets of responsibilities.

In Section A, I will explore this concept of disability competency, i.e. the idea that a disabled person has suffered a misfortune in their ability to fulfil desires which also conveys upon them a duty to develop skills, knowledge and practical wisdom in dealing with that misfortune. This knowledge must be acquired for both their own benefit and the benefit of those with whom they interact, and if a disabled person fails to develop such competency, they may be guilty of behaving irresponsibly, or even immorally. This is an idea certain brands of social theorists would doubtless frown upon, but one which I believe is absolutely necessary if there is to be any meaningful and cooperative relationship between disabled people and society.

In Section B, however, I will balance the portrait of disability competency by discussing the more familiar themes of social attitudes towards disability, and more specifically the idea of social difference as being the chief force in society's general perception of disabled individuals, a force which, if not universally negative, does have extremely unfortunate and negative consequences and should thus be considered as one which provokes immoral attitudes and behaviour.

In Section C I will assess the offshoot of the idea of an attitude of social difference and one of the main stumbling blocks in any reasonable discussion of disability: the problem of the assessment of a disabled individual's capabilities with respect to normality.

Also: John Swain, Sally French and Colin Cameron.

Also: Paul Darke.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

In Section D, however, I will conclude with a recommendation of how such capacities should be objectively discussed, and recommend a social change which could aid significantly in the discussion of disability even under my more liberal definition.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section A: The need for disability competency

In his theological novel *The Screwtape Letters*, C.S. Lewis (writing in the persona of a devil discussing how to tempt humans into committing sins) argues for a new understanding of several sins not merely in light of their literal, biblical meaning, but in light of their consequences to others.[169] Thus, Lewis (or at least the devil, Screwtape), argues that the "sinful" aspect of gluttony is not the quantity of food or drink which a person consumes, but the level to which those in a person's immediate surroundings are inconvenienced or directly harmed by a person's appetites. So, a woman who, upon being presented with a large and lavish meal insists that it is "too much" and that the chef take it away and give her "just a bit of dry toast" is equally guilty of committing the sin of gluttony as a person who will only be satisfied when provided with an extra, larger meal to the one originally prepared.

To place this idea in less overtly Christian moral terms, we could say that the woman in Lewis' example is behaving immorally since she is making no allowance for the feelings of the chef, or considering the amount of work she or he has put into cooking the meal. The woman is focused purely on the exact fulfilment of her desires as dictated by her biological or social needs, and is not prepared to modify her beliefs or perceptions of what will fulfil those desires to save the feelings of the chef, to ease the chef's workload, or even to acknowledge the achievement of the chef in creating the rejected meal in the first place. After all, she is far less likely to cause offense to the chef if she only eats a small portion of the meal, rather than demanding that the chef prepare for her an alternative, meagre in size though that alternative might be. More simply we could say she is treating the chef as a means, simply the provider of the fulfilment of her desires, rather than an end.

Of course, this is not to say the woman's need to consume less than the allotted portion of food is not a real need, particularly if it has a purely biological cause which she herself can do nothing about, rather than being (as Lewis implies) a personal preference based upon some social ideal of wishing to appear refined or dainty. However, it is in the subordination of the efforts of another individual to a person's biological needs, and the denigration of that individual to merely a means to fulfilling those needs without any consideration of how much work, effort or time is involved that she is behaving immorally.

Suppose, however, that the woman, in full knowledge of her abnormally small appetite were to ask, prior to the preparation or serving of the meal, that she is given a smaller helping, thus ensuring that the chef's efforts were not wasted. Such a course of action is consequentially no different from the point of view of satisfying the woman's desires, since in either case she will attain the smaller portion she requires, however, by asking the chef in advance she is both recognizing the efforts of the chef, and also being cognisant of the fact that, for whatever reason, her own desires require a different strategy of fulfilment to those

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[169]C.S. Lewis, *The Screwtape Letters,* (Audio literature, read by John Cleese).

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

which the chef would normally encounter, a strategy which may require extra effort on the part of the chef, and for which effort a specific request needs to be made.

This is a perfect illustration of what we might call disability competency and, despite its fictional source, a highly realistic one. Frequently individuals who have undergone a gastric bypass to remove a cancer or cure pathological obesity do indeed have such a reduced appetite that they can only consume an abnormally small amount of food at one sitting. The problems associated with a gastric bypass can therefore often cause issues with portion sizes in restaurants or when dining with friends, making it yet another illustration of the wide ranging nature of disability.

Thus, a major part of developing competency at dealing with any disability would seem to be simply the ability to consider the effects of that disability upon others and how fulfilling desires affected by that disability may impact upon them. This consideration could be overt and fairly straightforward as with the above example from Lewis, or something more subtle and less easy to quantify.

During her work on the social perceptions of disability, the sociologist Tanya Titchkosky, while pretending to be blind with her visually impaired husband, details an incident in which they enter a shop, attempting to buy batteries.[170] Passing the counter, which other customers are using, they walk to the back of the shop to an unused counter, and wait for an assistant to serve them. When the assistant does come, Titchkosky simply requests the batteries, with no politeness or acknowledgement that she is making a less than typical request, where upon the assistant simply grabs the batteries, deposits them on the counter and leaves. This forces Titchkosky to have to make a further request and insist that someone come to the disused counter so that she can pay for the batteries.

While the social attitudes of the assistant and their less than obliging stance on disability are certainly a factor (one which I will return to later),Titchkosky did nothing to alleviate the situation. She did not greet the assistant, make conversation with them, make any effort to be pleasant, or indeed acknowledge the fact that she was asking the assistant to perform services which wouldn't normally be part of the responsibilities their job requires when dealing with customers, i.e. fetch items from the shelves. She even went to a different counter and expected the assistant to come to her, rather than going to the counter that was in use and asking the cashier there for assistance, something which she definitely could have done (indeed it would have been easier to find a crowded counter for a blind person than an unoccupied one, especially if her guide dog was trained to find counters specifically as Reever my dog is).

Though it is fairly clear from Titchkosky's example that the assistant sought to keep visibly disabled individuals at arms length, an attitude which is sadly often seen in society, (I'll discuss this attitude further in Section B) Titchkosky neither recognized, nor attempted to

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[170] Tanya Titchkosky.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

alleviate this attitude, nor did she make any effort to present herself in the situation as anything other than a customer with demands that required fulfilment. Of course, Titchkosky, as a customer buying an item from a shop, did have every right to "expect" the assistant to perform the obligations required of an assistant towards a customer, even if those would be slightly different when dealing with a visually impaired customer, however it was her overall attitude towards the assistant and the situation which seems to have been lacking.

This is the key principle of the idea of disability competency: the recognition by a disabled individual that in asking others to assist in the fulfilment of their desires, a disabled individual, due to their status as "disabled" is often making a singular or unusual request, and requiring extra effort on the part of others to fulfil that request. In light of the acknowledgement that a disabled individual is making such a singular request, a disabled individual has an equal moral imperative to show particular consideration to the person who is fulfilling the request, whether that person is a shop assistant, paid help, or a family member.

This isn't to say that a disabled individual should not make such requests, or that individuals around them are justified in denying such a request because it is other than what would constitute the normally expected responsibilities or behaviour towards others in society, only that a disabled adult is required to recognize that the fulfilling of their desires is not simply a one way, slot machine process whereby a request can automatically be expected to be fulfilled as soon as it is made. Rather, such a request would seem to be a two way process whereby the disabled individual collaborates with another human (or in some cases an organization or institution), to have their desires fulfilled, such collaboration being assisted by a mutual fulfilment of desires between the partners, as detailed in Chapter 3. In one sense such cooperation is directly worthwhile to the disabled person as well, since the disabled person's cooperation with a non-disabled assistant in the fulfilment of their desires is also a way to directly promote empathy, and therefore assure that the non-disabled individual's desires will be attuned to those of the disabled person, rather than orders which the assistant is expected to simply obey like an automaton; orders which might well cause resentment and ultimately make the fulfilment of desires less, rather than more likely. Of course, there are far more reasons for a disabled individual to treat an assistant decently than just as an extended way of getting what they want, but it can't be denied this is certainly a major factor which most disabled people will directly experience in their lives, since cooperation in the fulfilment of desires is far more likely when both parties recognize the worth of each other and each other's efforts during the course of that cooperation.

Of course where a disabled person uses access aids or animal assistants, a further level of competency is needed to predict exactly how such things affect people in their immediate environment and make adequate allowances for such effects, while equally remaining aware of their own need for such aids and assistance and not down playing that need for others' benefit either. For example, a person in a wheelchair with an adapted car is often required to park their car both so that they do not inconvenience other drivers while

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

removing their wheel chair ramp from the back, and yet also still be in a position to have enough space to use the ramp themselves. Of course, balancing such needs for access, particularly if those in the immediate environment do not recognize that a disabled individual doesn't have a choice about using such aids, is not an easy matter and often takes a large amount of diplomacy, compromise and advocacy (a matter I will return to later).

It is also evident that while disability competency may be expected, just as politeness may be expected from an adult, i.e. a person in full recognition of their own disability who is able to understand its effects upon others, it is equally obvious that just as we recognize that a child has diminished moral responsibility for their actions, so a person with cognitive disabilities (and possibly certain forms of mental disabilities) cannot be expected to make this recognition of others to the same extent that a person with normal cognition or mental processes would. Again this is why, as I suggest in Chapter 2, certain categories of disabled individuals need to be regarded as having the status of children, though even in this status, as Michael Smith notes, children can learn consideration for others in the cooperative fulfilment of their desires, just as a parent would expect degrees of unselfishness from a child as it grows.[171] My sister for instance, though intellectually close to the age of three, has still learned the concept of sharing. For an adult, however, the inability to recognize the cooperative fulfilment of disability related desires should be regarded as a form of immoral behaviour analagous to any mistreatment of another person, such as insensitivity or rudeness.

Of course one of the most major problems in assessing a person's actual level of disability competency is that, like common politeness and consideration of others, there is little or no way that it can be quantified. A disabled person, as per the castaway test established in Chapter 1, adheres to different processes to fulfil desires and needs affected by their disability than a non-disabled person, and by definition this will automatically be a more arduous, effort filled process than that employed by individuals without that disability, simply by virtue of being disabled. However, as with much to do with disability, it would seem that disability competency is more useful as an acid test, as a way of measuring in any given situation whether a disabled individual is indeed considering the desires and effort of others with equal respect to their own, i.e. if a disabled individual is or is not behaving competently. Thus it is a moral duty towards others, rather than an intrinsically hard and fast rule which may be followed rigidly like a law. It is also evident that as a form of competency, disability competency is, like a virtue, something that may be gradually perfected and attained over time through practice, rather than something which can instantly be said to be present or absent in any given situation, indeed most people who have lived with disability and successfully interacted with non-disabled members of society have likely developed it.[172,173] So, we might characterize disability competency as the duty implicit upon a disabled

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[171] Michael Smith.

[172] Alasdair MacIntyre has associated disability most closely with virtue ethics. However, his formulation, though thoughtful and complex, sees the virtues attained through disability as intrinsically worthwhile in themselves, rather than virtues which exist a posteriori to the state of disability generally. While it is true that the

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

individual to learn the ways in which they may best and most efficiently deal with the effort costs and other preclusions of their disability, and most readily relate this to the effort taken by others on their behalf so as to behave in a considerate, rather than inconsiderate way. Of course this is a "duty" in its social and every day sense rather than a duty in the stronger, and more imperatively moral sense usually meant by philosophers, especially those working in a Kantian tradition. "Duty" in this sense means a matter predicated upon consideration for the good of others, such as "the duty of politeness", rather than more objective or exclusively rationalist concerns of "willing the good." While of course another term such as "obligation" could be used, in its conventional sense "duty" can also signify a strong   set of responsibilities towards others resulting from a person's position within a larger group, for example, the duties of a judge, a teacher or a doctor. "Duty," may also refer to an obligation caused by a less than equal relationship to another person, for instance, the duties of an employee or a tenant. Of course, the relations of power and obligation are not entirely one way even in equal relationships, since the land owner has obligations to their tenants just as the employer does to their employees, and where such relations were entirely one sided, e.g. the greedy employer exploiting their workers or the indolent employees shirking their jobs, the relation breaks down into one of enforced slavery and thus loses all sense of duty. As noted in the first chapter, disabled people are not slaves, i.e. powerless individuals thrust into a defined group which automatically relates negatively to the rest of society, neither, however, does a disabled person's status as disabled make them an aristocrat, i.e. a member of a privileged class able to regard their own desire fulfilment as taking primacy over the desires and well-being of those outside that class.

Following Nietzsche, Tassano argues that disability is actually a survival trait and that disabled people have an ability to trigger the pity of others, a position which is reinforced by the medical profession.[174] This argument is far from convincing, however, it does represent a worryingly common social attitude: that people feel resentful at the supposed special treatment disabled people receive (an attitude which even receives voice at higher political levels). I recall for example one occasion when, on a train a woman refused to move one seat

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virtue of competency I suggest here may have worthwhile properties outside and above its relation to disability, I am far more concerned here intrinsically with the idea of competency as a state which disabled individuals should attain in achievement of aneudaimon life for themselves and in consideration of others.

MacIntyre's conception appears to hold disability as an intrinsically neutral state in which certain virtues may be practised, whereas the definition I considered in the first chapter exclusively states that disability is negative, and thus the "virtue" of competency (if it can be considered such) is more a best possible way of dealing with misfortune, after all, if nobody suffered paraplegia, the skill of driving a wheelchair would be totally unnecessary. Though of course, just as driving a wheelchair may help a person learn patience, coordination and develop strength in their arms, disability competency may aid in developing other skills, in particular how a person relates to others, but it is not valuable exclusively because of the attainment of those skills.

[173] Alasdair MacIntyre, "Chapter 9".

[174] Fabian Tassano.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

over to allow room for my guide dog causing me to stand the entire journey, she exclaimed, "It's not my fault that you have special needs".

It is as a direct counter to the rationale which often underlies such unearned resentment, even if not to the actual resentment itself, that a concept like disability competency is required, and why, despite how inconvenient society often is, the reciprocal nature of the disabled person's relationship to those around them should always be remembered, both by the disabled person themselves and by the non-disabled members of society.

Of course, disability competency only comes into play when a disabled person is interacting on a personal level with others, which is why it might be characterized more as a duty born of politeness and consideration, than as a cast iron moral law; a facet of individual behaviour and attitude, rather than one of institutional or social justice. Yet, like many other forms of social interaction between people, it is a principle by which a disabled adult could be judged to fail or succeed in, both on a general, interpersonal level, and also possibly more broadly, just as someone with a rude manner or a lack of consideration towards others might be judged as acting immorally. For this reason, and especially given the social attitudes towards disability, it is a principle which I believe must be included in any discussion of the interactions between disabled and non-disabled people, especially if, as indicated, disability is such a wide-spread phenomenon. Thus, disability competency is an instrumental virtue which many people should acquire.

The potential consequences of failing to act with competency are even more serious than just the disabled individual's own inconsiderate treatment of others, since, when a disability is visible, it can influence individuals or institutions for, or against, anyone with that certain type of disability. When I first attended the Aims International Music School, the principal was extremely reluctant about accepting a blind person, particularly with respect to my guide dog. This, as it turns out, was due to a couple of blind people who attended the school previously and showed distinctly less than considerate behaviour, demanding services from others (such as picking up dog droppings), rather than making any efforts on their own behalf to assist others in fulfilling their desires. They also demanded ensuite bathrooms despite the fact that nobody at the music school has such a room, and the fact that the accommodations officer had already placed them as close as possible to the nearest bathroom facility. They were thus not only guilty of treatment of others purely as means, but also of a level of unrealistic expectation of desire fulfilment which did not fit their current circumstances or indeed bear any relation to what was "normal" in that situation and environment, all based on the fact that they were blind. Since, as humans, people are inclined to make judgements of any previously unencountered groups based upon the first member of that group they come into contact with, it is therefore of even more importance that an individual with a disability which is made evident to the non-disabled people in their surroundings, avoid prejudicing others further by inconsiderate behaviour, though this is by no means the only benefit from acquiring disability competency.

By Luke Hewitt

Of course, the attitude of people within society towards disabled individuals is not simply one of potential universal helpfulness, neither is it a blank slate upon which the actions of disabled individuals will be measured with no previous expectations. Therefore, in the next section I will examine social attitudes in more detail, and what the key features of a society's given prejudices and judgements about those with disabilities are, and how these features may affect a disabled individual's ability to fulfil their desires.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section B: Social attitudes towards disability

Havi Carel notes in her book on illness, that the attitude of others quite abruptly changed when she was seen with an oxygen cylinder.[175] She suddenly became known as "the lady with the oxygen"; it was the first thing people saw about her, and the thing people most frequently remembered. Similarly, Murphy notes that when he suffered an illness which confined him to a wheelchair, it was suddenly the chair that was the first and most important characteristic of his which people noticed.[176]

I have observed myself that upon meeting anyone for the first time, for the first five minutes often nobody will speak to or acknowledge my presence. Furthermore for the length of our first conversation people will speak slowly and carefully, as though I were easily offended or angered, or from a nation with a different first language to English. It is usually not until I have talked to someone for some time (usually half an hour or so), that they suddenly forget my eyesight, start consciously using expressions like "I see" as opposed to obviously avoiding them, and in general treat me the way they would treat another person, rather than as some unusual curiosity whose differences from themselves are something they are perpetually conscious of.

Government studies done in 2002 confirm this practice, that when presented with a disabled person whose disability is marked by a visible difference, most people will react at first by keeping the person at a distance, at arm's length, or even by actively ignoring their presence.[177] Similarly, those who are found to have a disability (especially a mental illness), often experience this form of avoidance from the public when that mental illness becomes apparent, as noted by Brülde.[178] Indeed, I remember a friend on one occasion being very reluctant to disclose to me the specific nature of a mental illness she was suffering for fear that it would alter my attitude towards her, and finally deciding to reveal the nature of this mental illness only because she thought (correctly as it happened) that, as someone with a visual impairment, I would not treat her differently or cease being her friend due to her suffering the condition in question.

Swain, Germon, Wasserman and many others see social reactions to disability as primarily negative, indeed in many social accounts of disability even derivatively negative, to the point where disability is defined directly by the majority's prejudice. I am not myself, however, convinced that society's attitude about disability can be so easily dismissed as universally negative, despite how marked most reactions I have encountered from others

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[175]HaviCarel, "Chapter 1".

[176] Robert Murphy, "Encounters: The Body Silent in America", *Disability and Culture,* ed. BenedicteIngstad, and Susan Reynolds Whyte, (London: University of California Press, 1995), pp 140-158.

[177]Ini Grewal, Sarah Joy, Jane Lewis, Kirby Swales, and Kandy Woodfield.

[178] Bengt Brülde.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

towards me are.[179] In many countries, for instance, such as Canada following the First World War, or El Salvador following their revolution, favourable attitudes to military veterans who suffered disabling wounds during the war spilled over more generally into a "positive" attitude held by many of the population.[180,181] This phenomenon of admiration for victims of war causing a general improvement of attitude towards disabled people also occurred in Britain, Canada, America and several other countries, where disability related services initially began as a direct way of supporting those injured in war, rather than as anything to do with "disability" in its purist sense.

Even on a personal level, the responses to disability can vary widely. Titchkosky, Smith and Swain all note, for instance, that often people show an extreme overt admiration towards disabled individuals, seeing even the conducting of daily tasks as worthy of praise, an attitude I have encountered myself.[182] On one occasion, for example, at a social function, when a lady found out that I'd travelled there alone with no assistance from others, her first response was, "Oh well done!" as though I had completed some sort of impossibly difficult task simply by travelling there. Murphy also noticed that he was perceived as less intimidating or threatening as a professor, i.e. a person with a certain degree of power over others, once in a wheelchair.[183]

While some commentators, and indeed many disabled people, tend to view this attitude of admiration in a primarily negative light (particularly since actually encountering it in reality can be uncomfortable), there is no denying that often the attitude is absolutely genuine, simply because people cannot appreciate what living with any sort of disability, but especially those which necessitate radical changes in a person's life, is like. Some commentators, such as Goering and Wasserman, primarily put this down to a negative general social attitude, even calling it "the admiration for a clever animal", however, again,

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[179] John Swain, Sally French and Colin Cameron.

 Also: Penny Germon.

Also: David Wasserman

[180] Graeme McCreath, *The Politics of Blindness: From Charity to Parity*, (Vancouver: Granville Island Publishing, 2011).

[181] Frank JarleBruun, "Hero, Beggar or Sports Star: Negotiating the Identity of the Disabled Person in Nicaragua", *Disability and Culture,* ed. BenedicteIngstad and Susan Reynolds Whyte, (London: University of California Press, 1995), pp 196-209.

[182] Tanya Titchkosky, "Chapter 2".

Also: Michael Smith.

Also: John Swain, Sally French and Colin Cameron, "Chapter 4".

[183] Robert Murphy.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

this seems a rather bitter dismissal of what is frequently a perfectly honest sense of admiration.[184]

On the other hand however, negative attitudes towards disabled individuals are sadly not infrequent. This can occur politically or institutionally, as noted by social activists such as Shakespeare, Swain, Davis and Germon, or more frequently on a very standard, personal level which people with perceived disabilities will encounter in their daily lives, sometimes on a regular basis. Negative responses and attitudes can range from a tendency towards avoidance, to distaste or covert snubbing, or even to complete hostility, mockery and violence.[185,186,187]

There are different causes attributed to these various social attitudes. Darke, for instance, assumes that people are afraid of the body images of disabled individuals, being examples of an imperfect body, though this does not explain the abnormal attitudes encountered towards those with mental or cognitive disabilities, nor the cases where positive attitudes are encountered (either genuine or exaggerated), since admiration, however misplaced, is rarely a response to apparent fear.[188] Several social theorists have, however, taken this idea of bodily imperfection to quite extreme lengths, leading to a complete phenomenology of disability. This phenomenology is based almost exclusively on rejecting the idea of "normal bodily experience", as in fact Titchkosky, Goering and Carel all suggest,

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[184] Sara Goering.

Also: David Wasserman.

[185] Tom Shakespeare.

Also: John Swain, Sally French and Colin Cameron, "Chapter 3".

Also: N. Ann Davis.

Also: Penny Germon.

[186] In 2009, the B.B.C. commissioned a documentary showing several disabled recipients of highly intensive abuse. This highlighted that disabled individuals were more likely to suffer violent attacks, name calling, and other forms of abuse. Anne Lewis also noticed that at school disabled children were far more likely to be targets of bullying. This is a fact that I myself have also unfortunately experienced. While it would be incorrect to assume that this sort of attitude is explicitly or implicitly universal, (as is implied by Swain and French and several other disability advocates), there is no denying that it does exist, and, as detailed by the B.B.C. documentary, unlike violence motivated by racism or sexism, there is no specific provision in British law to deal with the motivations of such attacks.

[187] *Disability and abuse*, B.B.C., September 2009, Television.

Also: Ann Lewis, *Children's Understanding of Disability,* (London and New York: Routledge, 1995).

Also: John Swain, Sally French and Colin Cameron, "Chapter 3".

[188] Paul Darke.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

though Carel's idea rests far more on a practical approach to experience of life, death and illness from the perspective of a body which does not interact with the environment as per a person's expectations of that body, following Merleau-Ponty.[189] According to this phenomenology it is not society, but the failure of the body as the centre of experience and the bearer of human intentions which is at fault, and others' attitudes can be seen as recognition of this failure.

Titchkosky's formulation of this phenomenology, however, is based purely upon the social construction of reality, and avoids discussion of specific bodily experience in favour of a critique of society's construction of an environment which she believes is naturally incompatible to those who have a "disabled experience". While Sara Goering specifically narrows herself to the opposition between "the disabled" as predefined social groups, and "the ableist construction of reality": a construction of the environment specifically designed to reject the experiences of those who are categorized as disabled. Others, however, offer a completely contrasting account of social attitudes towards disabled individuals not based on opposing phenomenology, but generalized social or cultural factors. Tassano, for instance, follows an account based upon Nietzsche's master/slave hypothesis, suggesting that society's function allows "the injured" to exert a moral pull upon the well for treatment of their injured condition, (though he doesn't deal with disabled individuals specifically, he does imply that they could be considered permanently ill).[190]

I am not, however, myself convinced by any of these accounts of the origins or explanations of the detailed mechanics of social attitudes towards disabled individuals, since those attitudes can be so completely diverse, ranging from avoidance, to hostility, to over protectiveness, admiration or distant politeness. For instance, if Szasz' hypothesis were universally correct, then disability should be an advantage for the moral reactions it arouses in others, while if Titchkosky's formulation were correct then it would be impossible for social institutions to conflict with the structure of reality by suggesting that disabled people were admirable in the way that war veterans, or disabled people sometimes performing mundane tasks throughout life are admired, (while this admiration might be seen as misplaced, it cannot be denied that it is genuine).[191]

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[189] Tanya Titchkosky, "Chapter 8".

Also: HaviCarel, "Chapter 2".

Also: Maurice Merleau-Ponty, *Basic Writings*, ed. Thomas Baldwin, (London: Routledge, 2004).

[190] Fabian Tassano, "Chapter 1".

[191] Ibid.

Also: Tanya Titchkosky.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Neither do basic explanations of "socially constructed reality" or "bodily image" explain the variance in different social attitudes to different levels of disability or how disability is perceived as a whole concept. For instance, those with disabilities that affect communication are more often pitied or thought stupid, as Koch notes, while those with a mental illness could be perceived as threatening, quite the opposite of Murphy's findings of the perception of those with paraplegia.[192]

It is also worth noting that frequently these phenomenologies, which extrapolate "types of experience" from social attitudes, are also couched in universally positive terms, in which the "Tyranny" of "ableist reality" is set against the "freedom" of "Disabled experience", giving them a distinctly political bias, i.e. explaining society's perceived attitude to a group whom the writer sees as "disabled" rather than trying to analyse attitudes towards disability as a whole. After all, while it's reasonable for a paraplegic person to claim that society's use of stairs is an environmental change which they experience negatively (albeit I am not convinced by attempts to link this to some sort of arbitrary, majority prejudice as Goering does), it's difficult to see, for example, a person with chronic depression claiming that their experience of the world is a valid, personal interpretation being oppressed by the majority's non-depressed view.

While there may be explanations for people's attitudes towards anyone with a perceived disability, such explanations I would see rather as a matter of the psychology of an individual, or at most the generalized beliefs that individual has absorbed from the group to which he or she belongs, rather than all being symptoms of any single, overarching explanation that covers all the multitude of classifications of disability and attitudes towards it. For instance, in Arthur Conan Doyle's novel *The Sign of the Four*, Colonel Shalto's fear of one legged men is a direct symptom of his guilt at how he swindled the one legged Jonathan Small, and thus purely a matter of his own individual experience and not applicable to anyone other than himself. More generally, people in El Salvador who perceived disabled individuals as worthy of admiration due to their association with war veterans, would seem to have a very different psychological history from those mentioned in the B.B.C. documentary who perpetrated sadistic or violent acts against disabled people, even when those individuals possessed similar disabilities, such as missing limbs.[193]

The one key factor, however, in the treatment of anyone perceived to have a disability, and the factor which seems to have most implication in an ethical debate is simply the fact that there is a distinct difference in the attitudes of most individuals and cultures

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[192] Thomas Koch.

Also: Robert Murphy.

[193] Frank JarleBruun.

Also: *Disability and abuse*

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

towards those perceived to have a disability, as opposed to those who don't. No matter where, when, or what nature the disability takes, most people will automatically assume anyone with a disability is, rather than merely being a similar sort of being to themselves who happens to have suffered a biological misfortune, a different kind of being entirely, and one requiring a different sort of response to that the individual would give to another able-bodied person. This response may be good, bad, admiring, avoiding or condemning as the individual's own psychological makeup or life experience dictate, however, it is still not the response the same individual would give to a non-disabled person.[194,195]

Since we do naturally have such a term as "disability" and groups identified as disabled to whom it applies, this seems to imply that individuals belonging to those groups will be perceived as requiring, not merely differences related to their disability, but differences of lifestyle, ethical value, opinion, thought and even choice. The apprehension of these differences often mean the desires and freedoms of disabled individuals are thought of and evaluated otherwise than the desires and choices of anyone else, and it is in the effect upon a disabled individual's freedom caused by these differences in opinion that I believe the moral implications of attitudes towards disability truly lie, not in their underlying cause or even in the attitudes themselves. These opinions of difference seem to be almost universal, and held to a greater or lesser extent by a vast variety of people, even people connected with disability related governmental services (a fact that Smith, Swain, Brisenden and Titchkosky all note).[196,197,198]

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[194] Of all the discussions of attitudes towards disability, I find Carel's careful explanation the most convincing, being based entirely on the individual experience of a lived body in the world, rather than specifically aimed at the idea of a socially constructed reality. Her formulation (unlike that of Titchkosky), however, is not exclusively directed at an explanation of the social attitudes towards disability, but rather a more general treatment of an individual's experience of illness, and therefore covers several issues that are not directly applicable to disability such as the perception of the nearness of death. Interesting as the phenomenology of a disabled or ill person's experience in the world is, however, it is not my main focus here. In terms of purely ethical considerations of the relationship between a disabled person and society, it is, I believe, the basic perception of difference that bears chief responsibility for the differing ethical treatment of disabled individuals, however that difference may be experienced or explained.

[195]HaviCarel.

Also: Tanya Titchkosky.

[196] Michael Smith.

Also: John Swain, Sally French and Colin Cameron.

Also: Simon Brisenden.

Also: Tanya Titchkosky.

[197] The 2002 governmental survey did suggest that the vast majority of people hold some differing attitude towards those with a visible disability. This is something I can attest to myself, since usually the only people who will instantly get over the, "He's blind!" reaction at first meeting me are those who have perhaps been used

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

While I was applying to universities to study a degree in philosophy, for instance, the disabilities adviser at one university (which shall remain nameless), said to me, "Why are you doing philosophy? Why don't you do computer science? That's what blind people usually do: everything is prepared." I do not believe this assumption was intrinsically malicious in origin, indeed I genuinely believe the disabilities adviser "thought" he was acting in my best interest in suggesting I do "what blind people usually do." Yet it is clear that in his assumption that "blind people" should have lives ordered in a very specific and narrow way, he was extremely guilty of the most literal form of prejudice, i.e. pre-judgement of a person's desires based just upon the fact that the individual happened to have a visual impairment, a judgement just as potentially harmful as judging that all women wish to have children or that all Indians eat curry.

This form of prejudice is one many disabled people find extremely damaging, being forced into doing what "it is expected" they should do, rather than doing what will best fulfil their desires. Indeed in many communities of disabled individuals it is automatically assumed that a person's preferences in life, desires and even language will be dictated exclusively via their disability, for instance, assuming that all blind people read Braille or that all those in wheelchairs will naturally have no interest in spectator sports. Among some disabled groups there is a conscious effort to "embrace the culture" of disabled experience, often a desire based heavily on beliefs in the majority/minority phenomenal construction of the world, as previously detailed, though this would seem more likely to exacerbate rather than alleviate social perceptions of the intrinsic difference of "the disabled" and thus perhaps even contribute to fostering radically other-regarding unethical attitudes. This idea of the nature of disability is one I will return to in the conclusion of this work.

The perception of difference is extremely overwhelming and encountered by perhaps everyone who has a disability when that disability is directly apprehended by others. This apprehension can range from an active avoidance, such as the well documented "Does he take sugar?" syndrome, where a person would rather talk to an able-bodied individual than a disabled one even about personal arrangements of the disabled individual, to a very minor, over-politeness or over-consideration. As Brülde and Szasz both note, it also intrinsically affects those with mental disability, and Chappell details its effects on those with cognitive disabilities.[199] Indeed, even individuals with one sort of disability can be guilty of this

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to encountering other people with a visual impairment (perhaps friends or relatives), and are thus used to thinking of visual impairment without an intrinsic moral or experiential difference. There have been some occasions when I have met unusually open-minded people who, through application of reason and life experience will consciously minimize any difference in thinking concerning visual impairments, but these are extremely rare.

[198]Ini Grewal, Sarah Joy, Jane Lewis, Kirby Swales, and Kandy Woodfield.

[199] Bengt Brülde.

Also: Thomas Szasz.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

unexpected perception of difference, as witnessed by the famous deaf/blind author Helen Keller's desire to avoid those with cognitive disabilities.[200]

Even the recent Paralympics can be seen as evidence of the "difference" of disabled individuals. While many people promote the Paralympics as a positive influence on social perceptions in recognizing the "achievements" of disabled athletes, it is still true that the Paralympics is a separate event from the Olympics itself, held at a different time and with different media coverage. Whereas heats for men and women are held in the "normal" Olympics, as well as heats for other categories of humans such as weight classes in boxing, when "disabled people" are competing it must be done in a "special" venue. Thus, if the Paralympics were truly to promote a positive and not "different" image of disabled individuals it really should occur as part of the main Olympic event, rather than as a separate, segregated one.

Yet, ironically, although this perception that disabled individuals are a "different kind of people" seems intrinsically false, it does contain a grain of truth, since obviously, if a disabled individual didn't have a disability, the difference wouldn't exist. Even under the definition I provided in Chapter 1, disability automatically implies a difference from the normal course of fulfilling desires, since manifestly, if a disabled individual did not need to take extra effort or suffer a biological preclusion of their desires, they would not be disabled in the first place.

In the more general social perception of difference, however, the critical factor is the moral and psychological weight this difference is given, since if disability is seen as just as common place a human problem as illness, being lost, being frustrated or any other sort of condition that alters a person's ability to fulfil his or her desires, then disability will quite obviously be a less exclusively "different" occurrence, or one which should necessitate a change in attitude, i.e. disabled people will (as I told the unhelpful university disability adviser) be "people who are disabled", not "Disabled people"

This indeed is already a main aim of several disability aids and practices, for example, assistance animals can often make social situations easier, a fact I've certainly noticed myself with Reever. While I am not sure of the psychological reason for this, I do sometimes wonder if it is because people find the more common experience of talking to a black Labrador easier than trying to address the "strange blind man".

Unfortunately, significantly altering the perception of "disability", from that of a state of difference to merely a state of misfortune, would take a major change in the social consciousness, and it is currently true that for a disabled individual, being treated as "different" is almost inevitable as soon as people perceive their disability. Though a

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Also: Anne Louise Chappell.

[200] J. David Smith.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

sufficiently competent disabled individual can take steps to alleviate this perception, provided that people are willing to change their outlook, often individuals and institutions are not, especially when that perception of difference is also tied up with the assessment of a disabled individual's capabilities.

Section C: Disability and assessment of capabilities

One of the most damaging aspects of the nearly universal perception of disabled people as fundamentally different types of beings from non-disabled people is the general misapprehension of the capabilities of disabled people. In the course of many prejudicial attitudes, the belief that a person who is a member of a given group is in some way "inferior", or unable through their membership of said group to perform some sort of activity, can be quickly and manifestly demonstrated to be false.

The early 20th century belief, for instance, that women were unsuited to intellectual activities such as mathematics and science, can be shown to be false by the examples of successful female scientists and mathematicians, just as the belief expressed in the title of a 1992 sports film, *White Men Can't Jump,* that Caucasians were inferior at playing basketball can be altered by the example of a skilful Caucasian basketball player.[201] So, we would expect that prejudicial beliefs based on inductive reasoning concerning that belief should be changed by the simple exhibition of a counter example. Of course, whether a group or individual will in fact reverse their prejudicial beliefs upon apprehending such a counter example is quite another matter, though it is hoped that any reasonably forward-thinking person will be able to do so, or at least on a basic logical level (as well as an ethical one) should do so.

With a disability, however, since by its very definition disability automatically implies that a disabled individual is unable to do something, prejudicial judgements about the capabilities of disabled individuals are far more complex, since while there are prejudicial beliefs which may be utterly unrelated to a person's actual disability, e.g. "people with paraplegia are not fun to be with," which may be similarly disproved as the above mentioned examples (for instance by experiencing a "fun" paraplegic person), there are also some restrictions implicit in the very definition of disability itself which, though perhaps not prejudices in the usual sense, do seem to be related in their imposition of beliefs that negatively concern another's capabilities.

By definition a person with paraplegia cannot walk, a deaf person cannot hear, a blind person cannot see, etc., are applications of that definition rather than a completely unfounded prejudice.[202,203] Some social theorists, and indeed governmental agencies bent upon political

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[201] As noted in the first footnote to Chapter 3, even if there are general racial differences, they are at most statistical only, and therefore just give a chance of variation, certainly not the justification for a categorical inductive judgement about what "all" members of a given racial group could be. Thus, even if there were a slightly greater likelihood of a good basketball player being of African descent rather that than Caucasian, it would not justify such categorical assertions.

[202] Some followers of the social model, such as Newell, Darke and Swain, intrinsically believe that the social definition of disability is one made up entirely of negatives for this reason.

[203] Christopher Newell.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

correctness, have tried to straight-out deny this fact by using phrases such as "differently able" or the even more confusing "handicapable", however, as governmental surveys show, such rebranding isn't usually taken well by the general public, and despite its use by some social model advocates, such as Swain and French, I personally, along with Titchkosky, am more inclined to believe such obfuscations are at best unhelpful, at worst actively damaging since they often serve to confuse rather than clarify the problems disabled people experience, after all saying, "A paraplegic person is able to walk with a wheel chair", is simply factually untrue, whereas saying, "A paraplegic person is able to be mobile with a wheelchair", makes far more sense and is a much more useful statement in any discussion of fulfilling a paraplegic person's desires.[204]

As noted in Chapter One, when discussing the definition of the word "disability", there is no getting away from the fact that disability is primarily and fundamentally a negative state, and therefore some beliefs concerning disabled individuals are inherently different from more irrational forms of prejudice, since, manifestly, presenting a walking person with paraplegia as a counter example to the belief that paraplegic people cannot walk would be logically impossible. Basically, a disabled individual simply will take more time, trouble and effort engaging in activities which are affected by their disability because they are disabled with respect to those activities.

The problem, however, is that the perception of difference mentioned in the previous section, whether positive or negative, affects not only those activities that a disabled individual's biological inhibitions preclude, but also many others as well, which is why, as noted in Chapter One, disability is a term of judgement, since even though under the definition I am proposing judging a person as "disabled" should theoretically only refer to that person's biological inhibitions with respect to certain desires, in practice when a person is said to be "disabled" the term bears significantly more social weight in the form of the perceptions others hold of that person as inherently "different". This is a facet of disability often commented upon, for example, Paul Darke notes that disabled individuals in western society, even when their disability is physical, are often believed to have impaired mental abilities or the emotions of a child rather than an adult, and thus are incapable of engaging in adult relationships or in aspects of society which are deemed to have an advanced intellectual content, like studying at the same level as those without disabilities.[205,206,207]

Also: Paul Darke.

Also: John Swain, Sally French and Colin Cameron, "Chapter 3".

[204]Ini Grewal, Sarah Joy, Jane Lewis, Kirby Swales, and Kandy Woodfield.

Also: John Swain, Sally French and Colin Cameron.

Also: Tanya Titchkosky, "Chapter 6".

[205] Paul Darke.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

On a more basic level, I have noticed myself that often people will assume that activities, such as climbing a flight of stairs or unwrapping a plastic wrapper, which do not implicitly involve the use of vision, are held to be more difficult because I have a visual impairment. This is I believe a direct consequence of the perception of difference, that because a disabled individual is fundamentally a "different type of person" everything they do must be in some sense different. Indeed I've often noticed that there is a very distinct moment when people stop treating me as "a blind person" which is usually also characterized by a cease of concern for how I will perform various everyday tasks.

One of the single most damaging effects of this perception of difference on the lives of disabled individuals is when a non-disabled person is required to assess the capabilities or attributes of a disabled individual in some way, such as a job interview or a decision on allotting tasks when working towards a mutually beneficial goal, or engaged in a cooperative effort. For example, I have often found myself refused positions in stage productions since it is assumed that my ability to sing and act is somehow adversely affected by my sight, despite counter examples of a number of blind performers, and of previous experiences I've had performing myself.

Still more problematically, when the task involved does impinge upon the disabled individual's biological preclusions, the assessor may be unfamiliar with methods which a disabled individual will use to get around such prohibitions. For instance, my brother (who is also visually impaired) when applying for jobs was three times refused due to the job requiring travel, and the interviewer's belief that such travel would not be possible without the ability to drive a car.

Of course, in these situations a straight question on the part of the assessor to the disabled individual would seem to be a simple and logical solution since obviously it can be expected that, while the interviewer may be more familiar with the requirements of whatever task he or she is interviewing a person for, the disabled individual themselves will be likely (if they are competent) to be the most well-informed about their own capabilities. However, such questioning is rarely, if ever undertaken, either because the assessor is afraid such questions would be offensive, or, ironically, would violate laws concerning disabled access, or still more worryingly, because the assessor believes themselves to be a better judge of the disabled individual's capacities than the individual themselves. Such a belief can again be traced back to the perception of difference and the belief in intrinsic, disabled incompetence.

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[206] Murphy offers a shocking, but realistic example of this when a colleague of his, though accepting that Murphy himself as a professor in a wheelchair was okay, stated that his university should not accept disabled students because they should go to another university "which has the facilities to handle them". This, as well as being a clear example of the perception of difference, also showed a distinct belief that disabled students couldn't for some reason be expected to participate on a similar intellectual level to non-disabled students in a "normal" university, and thus required some sort of specialist institution to "care for them".

[207] Robert Murphy.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Surprising as it might be, this attitude is more common than perhaps many people involved with disability relations would like to think. I was, for instance as mentioned above once told by a disabilities adviser straight out that, "Disabled people aren't always the best judges of what they can and cannot do," and stories of disabled individuals being refused jobs and similar positions by non-disabled assessors are worryingly common. Of course, a disabled individual, if indeed they are an adult and therefore responsible for their own disability, does need to acquire the necessary competency to understand exactly what measures they may need to take themselves to fulfil their desires which differ from those desires' normal fulfilment, and perhaps what desires to give up due to too great a cost of effort.

It is also equally true that a disabled individual may simply be lacking information on how to perform a certain task, and may require information from others upon how such a task could be performed, and how the costs in effort could be minimized, for example, as noted previously, a quadriplegic person who cannot use a computer would possibly be unaware of devices like head and eye trackers that might enable them to do so, simply by virtue of lack of information. This means that the simplest answer and the answer that I'd imagine many disability advocates would give, that such decisions should always be left in the hands of the disabled individual, will not suffice, since, after all, if a totally blind person offered to drive a taxi, there should be legitimate grounds for stating that such a skill was not (even with extensive assistance from others) within their purview. Thus, when a disabled person's abilities are assessed there is often a clear conflict of interest between a disabled individual who may or may not be competent and informed, and an assessor who may or may not be prejudiced or informed. Even though, as we would allow, the opinions of a disabled person would always hold more weight in making such a decision, in practice, unfortunately, usually the majority of the power is on the side of the non-disabled assessor. This is particularly true given that, as noted in the first chapter, "disabled" is a term with an intrinsically judgemental overtone, and that if a person is held to be "disabled" their ability to make decisions about other areas of life not affected by their disability, including their ability to assess their own capabilities is often brought into question due to the perception of them as intrinsically different.

The current governmental solution, having laws that state a disabled person cannot be excluded upon grounds of disability, clearly does not succeed, since this just means (as happened with my brother's application for a job) there is a refusal to discuss the situation and often the assessor will simply think of another, unrelated (and frequently flimsy) excuse for refusing to deal with the disabled person so they can deal with a non-disabled person instead. Still worse, the assessor might agree, but minimize the role played by a disabled person in fulfilment of a task or in a job I was once, as mentioned above, told that while I was allowed to be on stage in a production, I could only do so if I stood at the back and sang, and so I was never seen by the audience. Difficult though this problem of assessment is, however, I do believe there is a solution.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section D: Independent adjudication

In western culture for thousands of years, it has been established that when a dispute arises between two parties that impinge upon both parties interests, a third party with knowledge of the circumstances surrounding the disagreement may act as adjudicator. For example, if two next door neighbours argued about the legal boundaries of their property and where a fence should be placed, the decision would be taken to Civil Court and, if no settlement was directly possible between the two neighbours' solicitors, ultimately would be left up to a judge. We would assume that the judge would be themselves both impartial with respect to the disagreement, i.e. not in favour of the interests of either neighbour, and also possess the appropriate specialist knowledge of property law to make an informed decision. We would also suppose that being a qualified judge, a person would have some degree of experience, moral integrity and practical wisdom, and thus would be able to think of the solution that best fitted the problem in question, using both the law's general recommendations of what should be done in such a situation, and their own experience with similar matters they, or other judges, may have previously encountered.

Various professions, vocations and organizations have adopted similar practices when it comes to adjudication. In employment for instance, A.C.A.S., the Adjudication, Conciliation and Arbitration Service, exists to mediate in professional disputes between workers and employers, while in the British National Health Service, P.A.L.S., Patient Advisory and Liaison Services, exists to handle complaints made against the health service by patients. Similar bodies exist within the field of social care, and even with respect to activities such as sports, where general regulatory bodies such as the British Archery Foundation may be contacted to make independent decisions on disputes of the rules or management of those sports and those who play them. Like a civil judge, it is supposed these agencies are independent of the interest both of the ruling authority of the organizations they are concerned with (when such central authorities do exist as with the National Health Service) and the parties making complaints of them. It is therefore hoped this independence of influence, as well as a familiarity with the circumstances of the occupation involved even when not being intrinsically part of that occupation, plus a certain amount of life experience, will enable them to make reasonable, unbiased decisions which best serve the interests of both parties, or at least where they serve the interests of one party in particular, do so because one party's position is held to be the more reasonable.

As noted previously, though British law states that a person cannot be discriminated against directly on grounds of disability, this is more frequently a course for denial of disability related dialogue, since an assessor is not forced to discuss disability at all, and can still claim any other grounds or excuses for rejecting the disabled person's input, however competent that disabled person happens to be, even regarding knowledge of themselves and their own circumstances. Since the subjective nature of any disability and its possible

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

consequences means that the correct judgement of such an assessor, or (likely in less common cases) the disabled individual themselves, may not be objective, it would seem that a third party, a knowledgeable body to adjudicate and mediate disputes concerning disability, would be a logical answer.

Of course, such a body would need expertise in living with disabilities and fulfilling desires on a very practical level, and also in multiple types of disability given that the experiences of people with different forms of disability may be extremely contrasting. I once encountered a disabilities adviser who, while skilled in certain fields, had little to no experience of visual impairment and yet still sought to advise me on what I could or could not do (a fact not helped by said adviser's more general attitude of paternalism towards all disabled people). Also, such a body would seem to need to have its members gain their experiences of disability via a competency within life, as well as a purely academic study, and a competency which also would mean a respect for others' interests rather than simply a promotion of the interests of any disabled individual over those of an assessor. This is perhaps where certain current organizations for specific groups of disabled individuals may be less than successful, since their focus is upon political freedom for their specific brand of disabled people, rather than a more basic, or individualistic, examination of each disabled person's life and desires with respect to the expectations of those around them.

A further problem with the advocacy of individual groups for disabled people when applied to specific cases of discrimination is that it can be too easily dismissed by the non-disabled assessor as an incompetent judgement, since if an assessor is inclined to believe the capabilities of one disabled person are lacking, they are unlikely to believe better of groups representing that person's disability, whereas an agency which dealt with disability on a general level is less likely to be perceived as either biased in favour of one group, or less than competent themselves. One primary advantage of such an adjudication agency as well, is simply that they will start a dialogue with the assessor about the nature of disability, and therefore allow the assessor to become more familiar with the field of disability in general, as well as the particular needs of the disabled person in question. This is where so often the anti-discrimination laws currently in force tend to fail, since they reinforce the idea of disabled people as intrinsically different beings and discourage any discussion of disability, whereas a direct focus and dialogue concerning the needs and expectations of the disabled person and the assessor is much more helpful over all, both to the specific case in terms of simply discussing, rather than avoiding, any questions of disability, and in general in terms of getting non-disabled people to consider matters from a wider viewpoint. Indeed I can confirm myself that generally I have found it far easier when people address issues connected with my sight directly with questions I can answer, rather than avoid them, and indeed avoid me.

A further problem connected with institutions is that frequently an institution might simply not be willing to alter a given process to include the needs of a disabled person, and choose to reject that disabled person entirely instead, believing that it is the disabled person who is at fault for not following "the system" rather than "the system" which should itself be

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

adjusted in some way. This again is where the perspective of someone from outside that given institution who doesn't have a vested interest in keeping the status quo of "the system" could be invaluable, since rather than being seen simply as one person's objection which can be overridden as, "Well that person doesn't fit our system", they can represent a larger field of interest and thus encourage more fundamental changes. My brother, for example, was on one occasion refused use of his adapted laptop to take notes in a meeting with social services because it was held that "laptops were not secure", however, allowing my brother to use his laptop would also leave room for anyone with any form of specialized writing needs, or indeed anyone who preferred to type rather than take notes by hand. This indeed is, I believe, close to what Goering intends with her talk of changing "the ableist paradigm". Though it seems more likely this change would be achieved with dialogue and negotiation rather than with political rhetoric, neither does it seem fair to assign any inconveniences disabled people encounter in interacting with pre-existing systems as exclusively "ableist", rather than simply a consequence of the disability itself, given that, as already argued, the source of the restriction is not directly located within society's general practice.

Of course, some institutions, such as universities, already possess disabilities advisers. Such advisers, however, since they are attached to a given institution do risk becoming simply an adjunct to that institution, and, in a position of "giving advice", are not literally empowered to enact changes, even assuming that such an adviser would be willing to go against the institution which employs them to the extent of recommending that changes be made. Of course, as my brother and I found when applying to university, there is a huge amount of variation in such services, dictated by the personality of the individuals involved and how much those individual advisers would put the interest of disabled people against their overall institutions. However, with an implicit tie to a given institution and therefore an interest in maintaining that institution's good will, and the fact that the institution is not beholden to take any given advice from an adviser, the system seems less than effective.

This is where an independent agency with responsibility for only those categorized as disabled, and which was not specifically attached to a given institution, would have an advantage and though the problems of deciding who was qualified for such a position may be difficult, they are not insolvable. Independent adjudicators in other bodies exist and are trusted in many walks of life to make major decisions, particularly when mediating between individuals and larger organizations. I believe, only under the auspice of such an agency, one which possesses the power to enact a dialogue with those who attempt to assess the capabilities of disabled people in society and with the disabled people themselves, or their representatives in cases where the disabled person is not able to represent themselves (such as temporal impairments), that we will truly see large scale changes in the social treatment of any and all forms of disability.

Indeed, given that under the definition established in the first chapter and the concept of disability competency, disability may be seen primarily as an individual misfortune and the development of necessary skills and competencies to cope with that misfortune, such an

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

agency is not merely an anti-discriminatory body required for smoothing the relationship between two politically opposed groups, but a definite necessity for dealing with the temporary or permanent disability of any particular person related to a given institution's activities, after all if an employee with a broken ankle could discuss changes in the mobility requirements of their job through the interventions of such a disability adjudication agency, it would be to the benefit of everyone involved. I would model the workings of such a mediation agency on the mediation of sports bodies or other groups concerned with very specialist acquired skills, rather than with a legal avoidance of racism or sexism.

A.C.A.S., however, does provide a very good idea of the duties and positions undertaken by such a body, since (as a discussion I had with A.C.A.S. myself on their activities revealed), their chief responsibility is one of promoting dialogue and mediation, and eventually coming to solutions of disputes. This is possible because in any dispute between employer and employee, A.C.A.S. represents neither, but has the skills and experience to understand the positions of both and thus can promote discussion and, where necessary, forceful arbitration. Such an agency, like A.C.A.S., would ideally be government funded rather than being a charity, to both give it credit with the general public, and also maintain its financial, as well as literal independence from any specific group of disabled people. Membership would be by assessment rather than by specific qualification to ensure that members' individual experience and knowledge of disability was examined, much the same way that members of the judging committees of various sporting organizations are appointed based on their experience and knowledge of the sport as well as their character.

Disability, as noted previously, is an unfortunate circumstance that requires the gathering of a set of skills and competencies in order for it to be dealt with successfully. As with any other skilled position, judgements from those already skilled, with such judgements having social backing, seem to be the way forward, and would represent a social and political melding of the interests of disabled people with society, rather than another form of segregation enhancing the perception of difference.

As such an independent body would promote, rather than stifle, dialogue concerning disability, it is also hoped that over time society's perceptions of disability would change. In the current situation the law actively prevents disability competency being recognized within the public consciousness by prohibiting dialogue and general interest in disability. With more decisions being openly made about the skills of disabled individuals, it is hoped social attitudes would improve, and that the perception of difference would no longer play such a major role in people's thinking concerning disability, which would in turn enhance the ability of disabled individuals to fulfil their desires with the minimum of social hindrance, and the maximum of cooperation from others.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section E: Conclusion

Even when we define disability exclusively as an unfortunate circumstance caused by a medical condition, that does not remove the problem of the attitudes both of a disabled individual and those within society whom that individual interacts with. On the part of the disabled individual, it is necessary, if they are indeed recognizably and cognitively adult, for them to acquire a certain level of competency and understand the effects of their disability, how it relates to the fulfilment of their desires, and what those effects are upon others around them. Such recognition will allow disabled individuals to approach the fulfilment of their desires and how such fulfilment impacts upon others in a cooperative, rather than passive, manner, which will benefit both the disabled individual and those around them, and more broadly through the medium of social prejudice, other individuals with a similar disability.

Equally, however, for whatever reason, social attitudes towards disability nearly always imply a form of difference, that a disabled individual will, by the nature of their disability, be a different kind of person from the rest of society, a difference which extends well beyond just the influence of the disability upon a person's ability to fulfil desires. Because this difference affects anyone in society's ability to accurately assess the capabilities of a disabled person, there would seem to be a need for an independent agency, not immediately under the auspice of any one disabled group, to be created. Such an agency would be skilled in the idea of disability competency, to assist in such judgement and promote dialogue concerning disability, rather than avoid it. While such an agency would by no means be an easy solution to adopt, requiring administration and funding from the government, the current status of disability and its provision under the law, as well as the current narrow recognition of disabling conditions, is in no way an adequate response to disability by society, and is the reason why disability discrimination still exists.

By Luke Hewitt

Conclusion: The benefits of a desire based definition

Introduction

The definition of disability which I have proposed here, is not merely one which is a restatement or clarification of the previously mentioned social or medical views, it is a new definition, and may be used to counteract some of the problems associated with disability as it is currently conceived; problems which the social and medical models have not been able to adequately address such as effort and fluidity of classification. It is also hoped the model can introduce new ways in which disability may be understood, and through that understanding, attempt to foster better and more moral social attitudes and practices in the future, based on a clearer and more flexible type of language and dialogue.

The desire based definition may also be able to provide more immediate ethical considerations connected with disability and the treatment of those experiencing it, whether on the local scale of access interventions, such as what factors should be considered when putting up ramps to a building for providing wheelchair access, to the larger scale modes of policy and decision-making and the ways in which social attitude towards previously identified disabled groups may be improved over time. It also gives an idea of how any new medical conditions should be assessed, as well as clarifying the disabling effects of existing temporary conditions such as broken bones, indeed the idea that such conditions should be considered disabling at all, rather than forms of illness or malady is one further benefit of a flexible and adaptable concept of disability grounded upon conceptions of well-being.

Therefore, to conclude the discussion I will first examine the benefits of the system I have proposed, and then discuss how those benefits interact with our existing social and ethical framework, finally, I will conclude by discussing the concept of suffering and the overall existential benefits that may be had from a far more diverse theory of disability than the monolithic or partisan examples we have previously experienced.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section A: Alterations in theory and practice

The medical model as proposed rarely states why disability is a bad thing (as noted in Chapter 1), indeed on those occasions in which medical ethicists have proposed why we consider disability bad, they mostly argue (as Boorse does) that disability is a dysfunction as compared with an overall perfect standard for humanity, whether that is some notion of evolutionary design or cultural norms.[208] It does not seem, however, that whether a body is "performing its function as designed by evolution" (even if evolution can be said to "design" anything)is as significant a concern as to whether a person could live aneudaimon or happy life. After all, simple survival and reproduction rarely has much bearing on the way we think of our well-being and the satisfaction of most of our desires. For example, a person who did not want children would probably care little about whether they were fertile or not.

The cultural idea which Wakefield uses might have more merit, however, it still runs into the problem of exactly what a culture considers a good life, and, more problematically, what a culture considers "a good life" for given members of society. Emmeline Pankhurst, the famous suffragette, was not, according to the standards of her early 20th century British culture, being mistreated given how that culture viewed women, however the lack of overall freedom, the freedom to vote and participate in the process of democracy, clearly had an adverse effect upon her well-being, and that of many other women at the time. Less drastically, would we see an introvert in a culture which saw extraversion as the norm as being mentally abnormal if they were indeed happy with their own company?

Both of these notions lead to a tyrannical standard of normalcy, a notion that statistically abnormal deviations from the ideal, whether that ideal is cultural or evolutionary, are in some way bad only because they deviate from that standard, irrespective of what actual suffering they may cause. It is for this reason that theorists in the social model (quite rightly) wished to setup a system where disability was characterised as the mistreatment of various groups, and where a disabled individual could be said to be "suffering" simply by virtue of those goods, freedoms or considerations which members of those groups did not receive.

The problem here however, as previously noted, is that firstly there are many disabilities which do not fall into a quickly quantifiable "group," and secondly this method sees disability purely as a group identity, and assesses the lives of disabled people only according to their identification with that group, rather than an individual's desires or well-being. It also perceives reality as purely and distinctly conceived of as a group experience, and the experiences of lone disabled people are seen only as the internalising of beliefs they have picked up from society (as Jones and Titchkosky, to name but a few, argued).[209]

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[208] C. Boorse.

Also: J. Wakefield.

[209] R.B. Jones.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Disability, however, is not just a group experience. Whether it is the experience of a person suffering clinical depression alone and friendless, or an individual with a bone or muscle complaint knocking their teacup to the floor while making tea at home, disability has effects that exist over and above those individuals' experience as part of society, and likewise, can be said to encompass many groups, such as those with mental illnesses or P.M.L.D. (temporal impairments as I have characterised them). There are thus many who do not fall into the vision of an easily identifiable group whose mistreatment comes entirely from the perceptions, cultural norms or paternalistic practices of a larger society.

It was for this reason that I believe the idea of effort and of desire has to be part of disability: that a disability can mean a person's own individual struggle to live their own life and attain their own well-being on a day to day basis, not merely the ways in which they relate to others or to society; that in fact a person with an allergy who must carefully plan out their meals and take considerable time making certain to avoid food groups can still count as disabled, albeit their disability may be less serious than someone with a more wide ranging form of impairment or a condition with far more drastic effects upon life such as blindness, paraplegia or agoraphobia.

This, however, does create a problem, since while we would want to say that an agoraphobic is disabled, the same is not true of someone who is simply too drunk to leave the house. Neither would we wish to say that someone who finds performing complex mathematical calculations difficult is in the same category as a dyscalculic child struggling with basic arithmetic.

Thus, the notions of voluntary states and of the castaway test need to be part of a theory of disability, so that a disability could be said to be an involuntary state of a person, something which bad luck, injury or genetics had caused them to experience. Second, however, a disability must still relate to the concept of normality, but a normality composed not of a set of expectations or structuring of the world, but a normality based on a specific question: how would the majority of humans perform at this same task if society were no longer involved?

This makes disability both relativistic but also highly flexible, a state of relation to the act of desire fulfilment and well-being which will touch most humans throughout life, rather than a monolithic category into which a person simply falls. Disability is a relation between a person and the world, a faculty of their fitness, and as such is something which can be applicable in many situations, not the least to that overlooked group of disabled individuals, those who are utterly unconscious of their own status, by comparing their experiences and levels of responsibility to those of children, and categorizing them on a sliding scale not as some homogenous group, but as people trapped in a certain state of development, but

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Also: Tanya Titchkosky.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

nonetheless worthy of consideration with respect to that state in the fulfilment of their desires and their well-being within it.

This more flexible definition of disability therefore opens up a far more critical method of discussing factors such as accessibility and assistance, since when effort and desire enter into the discussion of accessibility, it is far easier to quantify the functionality of aids and assistance, and their relationship to an individual.

An aid, such as a wheelchair ramp or audible announcement of written information, can be judged as functioning correctly according to how well it fulfils the desires of the disabled individual who uses it, and whether it does indeed decrease the effort costs to those of a non-disabled person.

Of course, this is where disability ceases to be an individualistic matter, and touches upon interactions between people, since in fulfilling desires, a disabled individual must interact with those around them, and such interactions must be more than just those of agent and patient, oppressor and oppressed, or server and patron.

This is also where disability touches upon the possibility of animal assistance to aid in the fulfilment of desires, though the use of animal assistance also comes with its own set of problems and relationships given that a person must stand in the role of steward to their animal and be responsible for their animal's well-being as much as their own.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section B: Disability and social relations

Since a disabled individual under the proposed definition will have desires that interact with others, whether as bystanders or assessors, it is necessary that a theory of disability address the questions of a person's relations to those others, whether the disabled individual is having their capabilities assessed by another person, or asking another person for assistance.

It is here that an individualistic assessment of disability can be helpful, since it can separate out beneficial relations between the disabled individual and those around them, and note that such relations must be cooperative, rather than exploitative, and just as a disabled individual, as primary arbiter and judge of their own desires, stands in the best position to identify what desires might need to be disregarded or altered in their fulfilment conditions due to possession of a disability, so a disabled individual also has an inherent social duty upon them by virtue of the recognition of that disability to develop self-knowledge and competency.

This competency is more than merely a person's politeness, it is a recognition of the cooperation of others, and that others are people with their own desires and well-being which are just as worthy of respect. Developing this form of competency will be of benefit both to the disabled person themselves, and to others, since it will foster good attitudes on all sides and promote cooperation, both in the fulfilment of a disabled person's desires on the part of the non-disabled person, and in the disabled person's recognition that they are requiring such cooperation from others.

Of course, unfortunately, given that even if we divorce disability from society's expectations, it does not mean such expectations and attitudes don't exist, there is still a question of how non-disabled members of society regard disabled individuals and their capabilities. This attitude, whether it is one of admiration, contempt, enmity or simple avoidance, will often contain the factor identified by social theorists that those categorized as disabled are fundamentally different sorts of humans, with different capabilities even over and above those affected by their disability.

This is also where, it is hoped, a freer definition of disability may be helpful, if adopted over a longer period, since if a person who goes into hospital with a broken leg and has their leg in plaster is told, "Now you are disabled," it means that maintaining attitudes, such as those identified by many social theorists, of disabled people as a completely different, somewhat distant form of humanity will be far less likely, given that most people will then be categorized as disabled themselves.

Unfortunately, however, we are not at that point yet, and it was in recognition of this that a final recommendation was made, that of an independent adjudicator, an authority which, not being tied to the needs of a specific group or individual, could decide rationally

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

upon matters concerned with disability, just as other arbitration services function in other walks of life, from legal disputes to sports.

Again, in acknowledging that disability is a state at which an individual can be competent, a circumstance of life (albeit an unfortunate one) rather than a singular, homogenous difference, it is hoped that social attitudes would alter over time, and that the actively perceived phenomenon of difference be lessened by familiarity, and "being disabled" would eventually have the same bearing upon life as "being sick" or "being lost."

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section C: Disability, vulnerability and suffering

In this thesis I have attempted to formulate a new definition of disability, based on the idea that a disability is any condition which adversely affects a person's ability to fulfil desires and life aneudaimon life, as compared to someone without such a condition.

Ever since it was claimed disability was more than the monolithic, irreducible concept which medical science held it to be, the chief emphasis of the dialogue upon disability has been that of freedom. Personal freedom, such as that sought by Tanya Titchkosky, political freedom, as Germon and Swain argue in favour of, or freedom to use language and labels as noted by Harris.[210]

This is unsurprising, given that, at rock bottom, disability involves restriction, indeed in German the term for disability is *behindert*, a word which translates directly as "hindered" or "hampered". However, in most dialogues on the subject, it is always believed this restriction, this hindrance, is purely and simply social. Indeed, some authors such as Germon claim that disability by itself is an utterly neutral state and that, were society setup differently, a person wouldn't be disabled. It is interesting that the vast majority of actual examples they use for evidence for this come from people with hearing impairments, such as the famous cases of deaf parents who attempt to stop their children having cochlea implants.[211] Myself, I am not convinced these examples are that of "positive experience of disability" so much as desire to value a specific culture and language, one which (as the case of Martha's Vineyard shows) is also open to individuals with normal hearing if they wish (particularly since often those examples are given by writers who are not themselves disabled). Yet, a person who is deaf is still not free to have a complete audio experience of music, the sound of water, or any other sonic based experience, for all that a person with normal hearing may learn sign language and visual communication.

Still more problematically are the cases of thousands of disabling conditions that are not characterized by their own language and culture like deafness. Is the elderly person who, due to extreme pain, is now unable to perform a simple activity having a neutral experience? Or is the person with depression, so paralyzed by the sense of their own worthlessness that they cannot even walk to the shops to buy basic necessities, having a "neutral" experience? These are undoubtedly experiences intrinsic to the nature of disability, experiences I face myself on a daily basis. I would agree with Derek Parfit here, that attempting to claim any

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[210] Tanya Titchkosky, "Chapter 8".

 Also: Penny Germon

Also: John Swain, Sally French and Colin Cameron.

Also: John Harris.

[211] Penny Germon.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

experience of suffering is neutral is categorically incorrect.[212] And therefore, in the same way, to try and suggest "disability" involves some kind of neutral experience, is also simply illogical. Indeed, more than this, it is a straight-out denial of the intrinsic nature of what experiencing the world as being "hindered" by a disability really involves, albeit a denial fuelled often by the very real desire for social equality. Disability, however, is not a political cause, an existential limit, or a conspiracy of medical professionals. Disability is, as the German term directly states, simply and fundamentally, a hindrance. It is not something to be dealt with by the vast machinations of political campaigns or over-optimistic exegesis about "different" experiences of the world. It is humble, raw, and far more basic than that.

It would seem to me that the defining characteristic of disability is not isolation, lack of political freedom, or even an experience of illness. It is purely and simply the experience of suffering: suffering loss of freedom, increased effort in daily life, and unfulfilled desires.

Of course it is equally true that living with a disability and coping with such suffering will help an individual develop skills and relations to the world that are unique and beneficial, however to claim (as Elizabeth Barnes does) that such benefits automatically justify the suffering of disability would seem arrogant in the extreme, not to mention hugely insensitive.[213] Even in the lives of those experiencing cognitive disability, the nature of this "temporal impairment" means that, however happy they are in a temporary sense, they will not experience or appreciate more than they currently have. It is purely and simply a shame that I will never be able to discuss my thesis with my sister, or that she will never have the chance to develop her own intellectual expressions, valuable though her life is to her.

There are two possible responses to the suffering of others. Elizabeth Barnes claimed that though people were unequal, the neutrality of this experience means that we should essentially not do anything to change this inequality.[214] I, however, would see the correct response to suffering to be one of empathy, and a desire to alleviate it, and to give as many people as possible the chance to live anormal life.

I have therefore tried to formulate a definition of disability which shows that being "disabled" is not a state of permanent illness, membership of a special club, or a state imposed by society, but a unique relation between a person's intrinsic biological experience, their desires, and their environment. This is a relation which will affect most people at some point in life, even to a very minor degree. As such, the concept of "disability" and how it is treated needs to undergo a radical change, so that it is no longer an abstract partisan movement, but a common place state which we recognize and understand and will encounter on a daily basis. Thus concepts like "accessibility" are not optional extras to life, or only

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[215] Derek Parfit, "Chapter 1".

[213]Blergh

[214]blergh

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

applicable to specific sorts of people, but necessities for all, which should be as basic and crucial to our understanding of a person's relation to the world as "illness" or "location."

Unfortunately, such a change in public and individual consciousness is a long way off, and would require considerable shifts in both our day to day understanding, and overall social or governmental structures for dealing with disability. It is, however, my belief that such a shift would benefit everybody, disabled and non-disabled or (as would be the case with most people) potentially disabled.

I have lived all my life with a visual impairment. It is a static and unavoidable fact of my existence. On one level it has taught me much and allowed me to develop skills of valuing others, of memory, and appreciation of different senses. However, none of these are skills which I would have been barred from were I not born with a visual impairment. Most of the time, being visually impaired is purely and simply annoying, since while it might not ultimately stop me doing what I want, it does make a huge number of things more difficult, and not just because most people in the world are not themselves visually impaired. After all, while it would be great if all food items had Braille labels and people no longer avoided me because I cannot make eye contact, that would not give me the experience of seeing a butterfly or stop me frequently walking into doors and hitting my head because I have failed to judge their position correctly.

Writing this definition and re-evaluating my own experiences, as well as the experiences of my sister and other disabled people, I have come to the conclusion that whatever benefits can be gained from disability, it is purely and simply an obstruction, but not an insurmountable one. It is a negative state, and one that requires experience and perseverance to cope with, one which society and the attitudes of others can either alleviate or exacerbate but can likely never remove entirely.

I therefore offer this definition: disability is an everyday, common place relationship to the world based on desire, effort and misfortune. I hope that it will be used and understood and that, eventually, we will form a society which recognizes disability for what it is, a state of misfortune, but one which occurs to beings that are fundamentally like ourselves. When we encounter someone who suffers, if we are ethical beings we respond with compassion and attempts to alleviate their suffering.

Such attempts may not remove the suffering of disability, but will serve hugely to improve the lot of many people throughout the world, people who must live day to day with the hindrance of disability. Furthermore, in recognizing the universality of disability and treating it as a common place problem, we recognize something human, fallible and vital in ourselves and our own ability to fulfil desires, after all, there is no knowing when the whims of fate may place us into a disabled relationship with the world since nobody, except for super heroes, is invincible.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Section D: Epilogue

Since the initial completion of the main text of this work in 2013, five years have passed and the dialogue concerning disability has of course progressed, particularly with the changes in the global situation with regard to factors such as economic recession, austerity and the greater prevalence of the concept of diversity as a driving political and social force. Therefore in this epilogue I would like to consider some of that further discourse in the light of the desire based definition of disability I have proposed.

One of the most important papers published in this time is Michael Oliver's "the social model thirty years on"[215] in which Oliver addresses some of the main thrust of the criticisms of the model, reassesses its scope and notes the model's status in a post-recession world. A time in which economic pressure has caused governments to increasingly turn to "individual impairments" to assess stratified provision of disability benefits on a scale of perceived severity, governmental policies which Oliver believes are partly founded upon criticisms previously levelled at the social model, (like many proponents of the social model in Britain Oliver is heavily concerned with economic inequalities).

Oliver addresses critiques of the social model that focus on its lack of completion as regards explaining disabled people's experience and its inability to encompass many aspects of disability by simply stating that the model was never intended to be a comprehensive guide to all types of disability experience, nor to entirely replace the language of individual impairments, but to function simply as an ethical tool used to help improve the lot of disabled peopleby placing discussion of disability on the same footing as discussions concerning discrimination against other minority groups. It is interesting however that even as he espouses this softer more pragmatic approach, Oliver still talks exclusively in a language of "us" (the disabled), as opposed to "them" (everyone else), and speaks of the problems disabled people encounter in life only as "barriers" i.e. as obstacles imposed extrinsically upon a person by their environment, rather than as being in any sense contingent upon the intrinsic fact of possessing a disabling condition in the first place.

Thus, even as he apparently repudiates the hard line interpretation of the social model with which he is so often associated, Oliver still seems to be tacitly accepting that it provides the only way of discussing disability and disability related experiences, namely as the experiences of a discrete, exploited social minority and their opposition to the majority with their opposing "ableist" world view.

Part of my project in proposing an alternative approach to disability based upon the individual fulfilment of desires was to create a more universal platform upon which the experiences of people who are normally categorised as "disabled"; as well as those who may

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[215]Oliver, M. (2013). "The social model of disability: Thirty years on". *Disability & society*, 28(7), pp1024-1026.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

be experiencing "disabling" states of affairs may be discussed. This would have the advantage of addressing the very problem which Oliver highlights, that of governmental assessment, need and resource allocation. Since in making matters of disability more individualised rather than working on a blanket categorisation of disability we open the door way to using resources more effectively, and indeed of creating more opportunities (economic and otherwise), for disabled people. After all as noted in chapter 3, if there was provision to support disabled people who could undertake part time employment as opposed to either being fully employed and receiving nothing or entirely unemployed and receiving financial benefits, economic and social circumstances would considerably improvenot just for disabled people, but also for the government as regards provision of services and in another sense potential employers of disabled people too. Such assessments, and indeed the administration of such benefits would by necessity need to be made on an individualistic basis, rather than by blanket social reforms as I discussed in chapter 4.

It is also significant that Oliver, even as he acknowledges the lack of scope of the social model only addresses this lack as far as the model's inability to discuss other social groups such as age, gender or ethnicity, rather than the individual desires of any given disabled person. Again however, a language of disability which included the notion of effort and desires would more easily let us address occasions where a person's identity and defining characteristics were not what social group they belonged to, but the desires they had and the goals they wished to achieve, and "disability" could be understood in the light of how it frustrates those goals. There should after all be room in our discussions about disability to address the plight of a nut allergic gourmet, as much as a paraplegic dancer, not to mention cases of disabilities with less rigidly defined social groups attached to them such as mental illnesses or chronic fatigue syndrome. Generally, I am deeply suspicious of the practice of many sociologists and political advocates to wish to categorise (and more often than not simplify), people's identity and life experience to merely how they exemplify intersections between different sets of social demographics, assumptions which may or may not reflect a person's actual life experiences, hopes and desires. After all, just because having children is frequently held to be an intrinsic part of "the female experience", the decision of whether to actually have children or not is one which ultimately should be left up to each individual woman's desires and how those desires intersect with her circumstances and relationships. Any discussion concerning her desires etc would not therefore be merely a microcosm of a discussion of the cultural status of women and the perception of women's desires more generally.

This idea of singular group experience is one I have found worryingly prevalent in much of the literature concerning disability and society, particularly in more recent discussions both academically and in the popular media. The intensively adversarial tone of such thinking, its assumption of an umbrella category of "disability" and its inability to distinguish between biological and social obstacles in the lives of disabled people, or yet to determine ways in which people who might be disabled but outside the usual cultural boxes of disability, including those with unconscious temporal impairments might interact with the

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

world means it is a less than subtle instrument, and more often than not one used to promote emotional rather than rational responses. This is why I would prefer if discussions of a "disabled experience", i.e. a unique category of experiences and relations to the world shared by all disabled people were employed with extreme caution.

I also believe (as I mentioned in chapter 4) that it would greatly aid discussion of cases in which prejudices do occur, if we could discuss these prejudices as a separate entity from the particular disabling conditions that incited them and thus have a clearer understanding of how to combat them, rather than trying to assume that all or even the majority of the negative effects of a disabling condition are in fact "barriers" erected by such prejudices, since a taxi driver who refuses to pick up a person with a service dog, exemplifies a vastly different state of affairs to a taxi driver who cannot fit a paraplegic person's wheel chair into their car. Both are undoubtedly problematic circumstances, but the nature of the problem and any discussion of its solution will take a wildly different path as I outlined in chapter 3. This is where I also would hesitate in using heavily loaded, and emotive terms such as "ableism" despite the term's common usage in disability studies (especially in the light of the pragmatic discussion of the term "ability" I employed in the first chapter of this thesis.

Simon Hayhoe[216] also criticizes the monolithic nature of the social model in his 2016 article through the case study of theories of blindness and morality. As he explains, he works from the perspective of an epistemological model of the study of disability. This model focuses on the fact that theories concerning disability and "the disabled" are themselves constructed by authors with their own socio/economic biases and assumptions concerning disability and the experiences of disabled people. It is through these theories and their frequently unrecognized effects upon the disabled and how disabled people are perceived morally that discrimination may occur not only actively, through directly discriminatory legislation and practices but also passively, with supposedly moral efforts to "help the disabled" producing the opposite effects.

He illustrates this by examining the case of blindness and education in the 18th and 19th centuries, and notes how in the past there was an intrinsic link between a person having a disability and their basic moral nature, especially blindness, with "the blind" seen either as morally backward, lacking in reason or (in extreme cases), cursed by god, and frequently blind people were themselves involved in the establishment of so called "asylums for the blind" in the belief that segregation, and the encouragement of "hard work" was intrinsic to the promotion of good moral character.

Having experienced myself (if briefly), some time in a "boarding school for the blind" and having been told that it would not be of benefit to me to be at school with sighted people

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[216]Hayhoe, S. (2016). "The epistemological model of disability and its role in understanding passive exclusion in eighteenth dend nineteenth century Protestant educational asylums in the USA and Britain". *International Journal of Christianity & Education*, 20(1), pp49-66.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

who "did not understand what it was like to be blind", despite the fact that clique ridden environment was one I found if anything harder to adjust to than a normal primary school, I am in sympathy with Hayhoe's argument here.

That being said, while I see the value of categorising disability based theories according to the intentions of writers to construct reality about impairments, I am less certain that the essential reality of "disability" on a conceptual basis stripped of all external prejudice is a quintessentially neutral one, or in fact that it should be as per my castaway example mentioned in Chapter 1. Indeed, this is likely where my own attempt to codify and redefine disability likely comes into conflict with many theories and disability advocates especially in the social model, since while I agree with Hayhoe that the construction of moral reality plays a large part in the idea of disability as a whole and how disabled people are perceived by the general public, at the same time I maintain the belief that "disability" is an intrinsically negative state and were it not a negative state a person would not be disabled, albeit that "the disabled" be they "the blind", "the deaf" or any other pre-existing category of persons with disability are not themselves in any sense literally inferior or any the less worthy of being treated as Kantian ends in themselves than anyone else, though their lives will probably be rather more difficult simply by the nature of possessing that disability.

A more extensive examination of Hayhoe's position is found in his 2015 book on blindness and education[217] which expands both his epistemological model of disability, and further historical information on the development of theories of blindness following the enlightenment.

He begins by noting the inadequacy of the current system of education, and how that system is itself based on prior contentions concerning disabled people. By taking blindness as a paradigmatic example of disability and charting the development of concepts of blindness through history, Hayhoe attempts to show the philosophical origin of many assumptions about "the blind" which are central to both educational theories and social practice, and thus be in a better position to question these theories more generally. He begins by examining the construction of the concept of "blindness" and its place in the history of ideas, and how passive, as well as active exclusion has occurred through culturally practiced beliefs about the capacities of blind people and the "appropriateness" of certain artistic, aesthetic or vocational experiences, he then expands upon his idea of the epistemological model of disability (mentioned above), as applied to blindness, explaining the model, the relationship of categories of disability to impairment and reality, and the inadequacies of assuming both an objective reality for disability in general and blindness in particular following the thinking of Foucault, noting that theoretical construction of disability has often been based upon lopsided power relations, though he repudiates the basic idea that disability is simply analogous to racism or sexism.

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[217]Hayhoe, S. (2015). *Philosophy as disability & exclusion: the development of theories on blindness, touch and the arts in England*, 1688-2010. IAP

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Of course, Hayhoe's project differs markedly from what I am attempting here, particularly since his book is partly intended to question the currently existing pedagogy for teaching blind students, thus where my own efforts in this thesis have been to try through both clarification and linguistic analysis to provide a more useful definition of disability that aides in equalitarian ethical discourse, Hayhoe's work is more a matter of examining the historical and theoretical routes of our existing concepts, how those concepts were used in the past and what theoretical frameworks they may have contributed to, and how those frameworks might fall short due to this load of frequently unrecognized epistemological baggage.

Hayhoe begins with a detailed examination of the concept of blindness in the enlightenment, how it became a tool of epistemological enquiry into the theory of knowledge for Locke and Newton, and Diderot, and how the corollary of the "man blind from birth" was used in discussions of aesthetics, morality and even Christian theology.This gave the definition of blindness a heavily political slant in the politics of the reformation since the "man blind from birth" was used as an archetypal example of acquired rather than innate knowledge, which lead (along with the real world example of many people who'd become blind through contracting syphilis), to a conception of "the blind" as inherently inferior on a moral, intellectual and even spiritual level due to a flawed ability to apprehend knowledge and moral teaching.

Hayhoe therefore contends that it is the ontology of blindness created by this philosophical discussion which then led to the uniform categorization of blindness as a singular set of symptoms analogous to a mental disorder. "Blindness" constituted a breakdown in perception which could only be treated in a stratified environment with a specifically tailored pedagogy, a pedagogy derived from the very philosophical enquiry and political power playing which created the ontology of blindness in the first place. The antecedents of this ontology Hayhoe contends continue to affect both the study and cultural perception of blind people to this day.

Hayhoe continues by making a comprehensive study of much of the psychological work on the aesthetic perceptions of blindness and assumptions underpinning such psychological research, many of which can be linked back to the previously detailed enlightenment theories about moral knowledge.

Having experienced the practical effects of some of these perceptions myself, I definitely agree with Hayhoe's historical construction here. Indeed even in philosophical circles I recall a good natured debate in an aesthetics class about the representative quality of smell in which the lecturer claimed that it was my lack of visual sense which let me attribute aesthetically representative qualities to other senses which they did not necessarily possess, a discussion which mirrors several of Hayhoe's findings about the insistence of psychologists even in the twenty first century on perceiving lack of sight as automatically translating into lack of artistic understanding.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

It is also possible that the "Arm's length" reaction I mentioned in chapter 4, whereby people tend to perceive me as an exclusively different being and at least unconsciously avoid me might be partially due to a lingering legacy of this ontology.

Hayhoe then extensively charts the development of educational establishments for the blind, noting the link between blindness and immorality and how throughout the 19th and even into the mid 20th centuries such institutions promoted repetitive handicraft and docility as a way of avoiding the supposed immorality in blindness. Even when institutions for the blind did include creative arts like music, this was usually done in a mechanical, rather than theoretical form emphasising rote learning as opposed to detailed knowledge, though he does note the different methodology of Worcester college and its higher level of creative learning due to its catering to blind sons of gentlemen from the upper classes.

Interestingly enough, Hayhoe's findings about music mirror experiences I had at the specialist school I attended for two years in the early nineties, where music was presented exclusively as a set of tasks or exercises to be accomplished on a rote basis, where any theoretical teaching was presented only in a subordinate manner to accomplish those tasks, and failure at those tasks was seen as being literally immoral (I was once told if I could not conform to the rules in musical practice I was destined to go to prison). I find it significant that despite two years music tuition at specialist school (including their abortive attempt to teach written braille music), I only learned about matters such as time signatures, musical dynamics and indeed any sense of artistic expression from a sighted flute teacher with no exclusively specialist training. Indeed I suspect had it not been for her I would likely still regard the practice of music as systematic drudgery.

Hayhoe then explains the founding of the famous disability education act of 1981, and how this act's composition and implementation was heavily influenced by the political climate of the day, including a notable financial crisis and the opposition of certain elements of the House of Commons to inclusion of disabled students in mainstream schools.

Hayhoe is of course here primarily focused upon historical detail (particularly in matters of education), while my focus has been upon the ways in which barriers to desire fulfilment may be used as a way to more ethically discuss and categorise disabilities. It is significant however that Hayhoe's exhaustive examination of the construction of the concept of blindness frequently highlighted inadequacies in discussing the desires of blind people, inadequacies which I naturally found interesting on both a personal, as well as a philosophical level having daily experience of them myself.

For instance, Hayhoe notes that having a degree of usable vision is often outside people's concept of what being "blind" involves, so desires of blind people who do want to appreciate things in methods other than touch or audibly are frequently forgotten, yet if the question is asked according to desire fulfilment, for example my desire to "watch"; or at least experience a film is more readily met by a DVD which includes audio description of the

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

action, than by just providing an audio described soundtrack devoid of visuals as is the more common practice of organisations for the blind in the United States.

This is also a clear example of the tension that can arise when attempting to establish a singular form of experience and methodology for a given disabilityand the individual desires of a group of disabled people, particularly when the historical construction of that methodology is itself of questionable provenance. Indeed it is interesting that so many of Hayhoe's criticisms of the construction of the concept of blindness are directly linked to tangible inadequacies in the education system in dealing with blind people through passively, or actively exclusionary practices, i.e. practices which directly affect the individual desires of blind people through say inadequate provision of teaching tools for conveying knowledge.

Similarly, I was amused by the fact that such a lot of philosophical heavy lifting and conjecture had gone into mythologizing concepts about which myself and other blind people are quite familiar such as two dimensional representation, indeed Hayhoe's examination again unfortunately proves the point that I mentioned in chapter three, that disabled people are often deliberately placed in a position where not only their desires, but also the necessary steps requisite to the fulfilment of those desires are dictated by others. For example, I recall an occasion in which a teacher at my specialist school severely berated me for saying I'd "read" a book through audio, since according to her I was incorrect to speak of having "read" a book unless I'd done so in braille.

One issue I did find in Hayhoe's discussion however is that frequently I have noticed myself a tension between main line policies of disability inclusion and the personality of those on a practical level who implement those policies.

This indeed is why I included an extensive discussion of human assistance in chapter 3 and spoke of cooperation in desire fulfilment, since frequently even when an intrinsic environmental barrier exists, an adequately ethical human assistant can make a direct positive difference to the fulfilment of that desire, or less happily, even when a policy exists to adequately aid in a disabled person's desire fulfilment if those who implement that policy on a practical level are basically disinterested the entire process is likely to fail.

Hayhoe offers a characteristically detailed discussion concerning access for blind people to museums and the theoretical underpinnings of that discussion based on the idea of touch as representation. He notes that when accessibility measures were in place, staff would be trained in their implementation, yet I remember a stark contrast between my experience at Blenheim palace and at Luxor in Egypt.

Blenheim had obviously attempted to implement a policy for blind people. The tour guide had a list of items which could be handled and historical information to impart. Yet, what actually happened is that in each room, the tour guide consulted a clip board, pointed at an object and said "you can touch that" before reeling off a historical description of the room in general which did not mention the history or prominence of the object in question. Had I

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

not been there with someone sighted I am not sure how I would have even knownwhat objects were available for tactile examination, let alone got more from the experience than a general audio tour which I might as well have done electronically at a distance for all its level of interaction with the historic location.

This contrasts markedly to my experiences in Luxor, where there clearly was no specifically tailored or implemented policy to cater to blind visitors, but a tour guide who was more than willing to carefully guide myself and several other visually impaired visitors around the site, explain intricate details of what was visible of the ruins and walk distances in space to estimate the Hight of objects or the features of maps to give an idea of scale. The tour guide even helped in a carefully limited tactile examination (which given the age of the stone work was quite an honour), and presented a narrative of the time of the Pharaohs, involving myself and other blind visitors in an explanation of Egyptian history so enthusiastic that it verged on improvised theatre.

This is one reason why I would like to see "desire fulfilment" become part of our usual discourse on disability, since in the promotion of disability as inherently a state of misfortune and those experiencing disability as intrinsically similar to other humans, we are far more likelyto be in a position where we would be able to engage with desire fulfilment cooperatively alongside an assistant, rather than being at the mercy of a policy which presents accessibility as something which is "given to" disabled people.

Of course, such a state of social acceptance is a long way off. Still it would have been appreciated if the training of the staff at Blenheim was more focused on giving blind visitors an analogous experience of learning history interactively, than a tick list of predetermined access requirements which in the end proved anything but satisfactory.

Hayhoe finally reaffirms the basic tenet of his epistemological model, that the construction of the concepts of disability is intrinsically linked to the background assumptions of those who formulate such definitions which frequently colour their estimation of the capacities, capabilities and moral status of disabled people. Such definitions are then utilised by those in power who may not themselves even have the good of disabled people as an end itself, and may be motivated by political or other interests in their formulation of disability related policy.

This conclusion I do agree with, indeed in one sense Hayhoe's intensive study of the history of the concept of blindness and its application in education very much supports both my arguments on the perception of "the disabled" as exclusively different types of beings outlined in chapter 4, and also the problem of the dictation of desire fulfilment noted in chapter 3. Indeed Hayhoe's epistemological model and detailed historical analyses serve as a complement to the desire based definition of disability I propose in this thesis, it provides a unique theoretical platform from which to analyse and critique the beliefs, practices and social status of various disabilities on a broad cultural and political level without needing to subscribe to umbrella categorizations of disability or try to give exclusively social

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

interpretations to the experiences disabled people have in their daily lives, and also allow room for the classification of different types of disability with alternative epistemological antecedents.

Education was also the focus of a 2014 article by Lasidu,[218] in particular she attempts to address why disabled students are underrepresented in educational institutions. She details her belief that the reason disabled students are not participating in higher education is due to a focus on special educational needs and a pathologizing of disability. As an alternative, she recommends "inclusion" and a "social justice" dialogue concerning disability which could be used to create a universally designed generic curriculum. As with much of the dialogue concerning "ableism" however, Lasidu's points are not so much argued theoretically as stated in a broadly categorical fashion, and one which furthermore seemed to focus upon concepts with little to know sense of practical definition, or (somewhat ironically), much idea of the experiences of disabled people.

For instance, on the one hand she castigates universities for not being "accessible" and then on the other states that methods to provide assistance to disabled students are contributing to their negative self-perception and trouble accepting their disability.

Her one attempt to provide any practical evidence of this is to repudiate the practice of disabled students being given extra time or a separate room for exams which (according to Lasidu), singles them out as "different".

I myself had both a separate room and extra time during exams due to the need to read a braille exam paperand to print my own answers afterwards. I can only imagine how the loud clank of my printer through a silent examination hall would have contributed to "social justice" between myself and other students, and I know exactly how "different" I would have felt if I'd constantly been having to pick up a braille exam paper due to it falling off a standard sized desk. I don't imagine such factors would have contributed positively to my final marks either. Lasidu's blanket assertion regarding exams also does not take into account students whose very disability might be directly impacted by the examination environment, such as autistic or agoraphobic students whose stress levels would be directly served by being treated as "different", indeed Lasidu is so mired in a strictly us/them notion of disability she barely acknowledges that different forms of disability may even exist, which makesher constant invocation of terms like "accessibility" less than clear.

In terms of ability generally, Lasidu asserts both "disability has no effect on the ability of disabled people in higher education", and also rather incongruously that "disabled people require support services", indeed she makes much of the fact that students with invisible disabilities are frequently slow to utilise those services for fear of being recognized as disabled. Yet if abilities are simply "different" rather than negative, why exactly would

[218]Liasidou, A. (2014). "Critical disability studies and socially just change in higher education". *British Journal of Special Education*, 41(2), pp120-135

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

disability services be needed in the first place, and why, to return to the example of an exam, would a student require any "different" adaptations such as extra time, more space or even just breaks if their disability had no negative impact on their performance.

While I appreciate Lasidu's attempt to recognize that social inclusion by non disabled students can contribute to the experience of higher education, her vague proposal of "promoting social justice programs" does very little to explore why in fact disabled students might have social issues, or indeed any of the beliefs or practices inherent in them, similarly, if her assertions about no difference in ability are true, how exactly would we solve such inequalities if they do arise.

For instance, it would seem that providing a student with mobility difficulties some accessible form of transport would do more to facilitate their participation in university activities than imposing a "social justice program" which might even have the opposite effect. I am also not convinced by Lasidu's argument that the chief reason for disabled students dropping out of university is lack of "inclusion" rather than say the extra effort required by a student with disabilities in completing the course, or more critical and substantive lacks in practical access arrangements, such as access to reading material, getting around the campus etc; lacks which would seem more in need of straight off pragmatic solutions based around discrepancies in a disabled student's ability to achieve basic constituent desires in education than some vague overarching plan of promoting "social justice".

Lasidu does acknowledge that financial reasons might have a part to play in disabled students not attending higher education institutions in the first place, especially with the dramatically increased tuition fees introduced in the 2012 education act and the fact that many disabilities naturally incur financial costs, however she does not explore this avenue, preferring to side with the rhetoric of how disabled students are "devalued" by the "able bodied order" rather than offer any sort of detailed analyses.

There is also a direct inconsistency in the way Lasidu deals with disability. She states early on that disability should be part of "social justice" and directly references the social model, and yet later, in the discussion of her idea of a generic curriculum she asserts that the disabled/non disabled dichotomy is itself a product of the "able bodied order" and the glorification of normalcy. Indeed, her notion of a "universally generic curriculum" in itself seems deeply problematic since if indeed as she asserts all knowledge in educational establishments is in some way value driven and built on unequal power relations, how exactly would a universally generic curriculum actually decide what to teach? With her repeated desire for a pedagogy which focuses on the social justice of disabled people, and her veiled assertions about educational establishments being exclusively involved with the capitalist job market and being products of the "able bodied order", Lasidu appears to be suggesting that the only valid matter of study would itself be disability studies.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

It is exactly this sort of abstracted rhetoric that highlights the need for a desire based analyses of disability which can focus on factors such as effort, after all if a person's desire when attending a higher education institution is to acquire knowledge, any discussions of "accessibility" must be understood in light of that desire, as the example of the examination paper shows. Likewise "inclusion" in a social sense would mean very little if a disabled student's individual problems involving effort and access were not met, indeed this is something Lasidu herself recognizes, albeit her assertion of inclusive teaching methods incorporating accessibility seems more an attempt to include the notion of individual access and provision for a disabled person's needs by another name.

The idea of disability as an interaction between a person's basic physical or psychological state and the external environment has recently been noted by the world health organisation[219], who in a recent report strongly emphasized the problems associated with environmental access to services and social interactions experienced by disabled people. However, just as with Oliver's work again the main focus was upon "medical conditions that cause impairments" and environmental factors that affected those impairments, thus making the report not only heavily based around existing and recognized categorisations of disability, but also slightly begging the question of what features of disabling conditions made them disabling in the first place. Indeed, The WHO report seemed to be more formulated as a tick list of currently understood disabling conditions with a handful of generalised bad effects such as lack of access to services than anything strictly definitional.

The WHO also manifestly take a rather strict "black and white", "us and them" mentality analogous to Oliver's, as regards "the disabled" as opposed everyone else, thus making their definition more a hymn to the status quo than a method for actually defining or discussing disability itself more directly, much less being able to discuss cases that did not fit as readily into the usual culturally predefined "disability" boxes.

This is likely why Hayhoe criticises the WHO definition for its reliance on a singular, monolithic concept of disability as impairment and notes its basis on prior ontologies of disability with their own historical and cultural bias.

Not all writers have adhered to standard definitions of disability however. Karren O'Connell[220] attempted to question the scope of the concept of disability by asking whether the category of "eccentricity" might provide a bridge between disability and normality in more complex legal cases.

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[219] WHO (16 Jan 2018) Disability and Health, *WHO Factsheet*, [online], Available at URL [http://www.who.int/mediacentre/factsheets/fs352/en/]

[220] O'Connell, K. (2017). "Eccentricity: the case for undermining legal categories of disability and normalcy". *Continuum*, 1-13

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

She gives two case studies, the one of a man with a mental illness whose constant vociferous complaints to his local authority caused so much major upheaval and upset he was taken to court, the other of a woman who was evicted from her housing estate due to her extreme psychological dependence upon her dog.

These however would seem to be exactly the sort of cases in which a more wide ranging definition of disability than the strictly us/them based criteria which has dominated social thinking up until the present time wouldbe of use, especially in codifying the voluntary or involuntary nature of disability itself and addressing such cases with respect to the virtue of disability competency which I mentioned in chapter 4. O'Connell defines eccentricity solely as being that class of behaviours and attitudes which is outside of social norms. She does not call these disabilities, yet is at lengths to point out that such behaviours or attitudes are both necessary parts of the identity of the individual who engages in them and so are behaviours which said individual cannot relinquish, and yet also behaviours which can affect that individual and those around them in adverse or harmful ways.

What is odd, however, is that if one adopts a desire based definition of disability there seems no need for such an extra category at all. On a basic legal level if the lady with the extreme dependence on her dog were classified as disabled, and thus her dog defined as a disability aid or "therapy dog" then the case would be quickly and easily solved. Indeed it is strange that O'Connell takes considerable time pointing out said lady's generalised distress in her life and extreme loneliness and depression and how such feelings are alleviated by her dog, yet does not acknowledge that the lady might be disabled simply because she has not seen a mental health professional and been diagnosed as having a mental illness; i.e. a disability. This would seem however, to be more a failure of the mental health services in her local area in not diagnosing her correctly, and the law in O'Connell's native Australia in not allowing mental health assistance dogs than the legal categorisation of disability more generally. Indeed in the United States assistance dogs for people with a mental illness already have the same legal status as guide dogs and other forms of assistance animals for disabled people and thus could not be forbidden by a landlord, and a campaign is currently in progress to have them accorded a similar legal status in Britain.

Even in the second case, that of a man who felt it his moral duty to so harass his local council with abusive phone calls and letters that they took him to court, it still does not seem a specific category of "eccentricity" is necessary to discuss his behaviour. If indeed (as he claimed), the man's behaviour towards his local council was in fact involuntary, then clearly he needs to be regarded as having desires which are affected by that involuntary state and is therefore disabled, just the same way a profoundly frightened agoraphobic who screams at any visitor to leave them alone is suffering a similar disability. It is also worth noting that if this man was indeed both unconscious of the harmful effects of his own behaviour upon others, and unable to refrain from such behaviours, then it would seem quite legitimate to categorise him as "unconsciously disabled" and therefore need to have another person engage as his proxy with regards to his interactions with the local council (a state of affairs which

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

would also alleviate the situation since the man's proxy could engage with the council without said man's intense anger or abusive manner). I found myself wondering why nobody had actually asked this man "If the council annoy you so much why don't you have someone else ring them for you?", the engagement of such a proxy and having the man himself understand his own mental illness would also be a chance for him to exhibit disability competency, just as a phobic might avoid contact with others when in a stressful or phobic situation to reduce the risk of harming others through their panicked reactions.

If however on the other hand the man was indeed conscious of his need to engage in harmful behaviour but simply did not care about the feelings of those at the council he upset, then he might well simply be a free agent engaged in abusive behaviour and thus both morally and legally culpable.

Indeed, O'Connell's equating the voluntary and harmless behaviour of eccentric artists and poets or those who choose to dress in an outlandish fashion, with behaviours that directly harm others such as the man in her second case study is not a corollary I find convincing, particularly since frequently those engaged in simply out of the ordinary eccentric behaviour might well moderate their actions if indeed they do cause direct harm to others. For example, on the occasion I myself participated in a choral concert singing John Williams music from Star Wars and chose to dress in Jedi robes even though nobody else dressed that way, something which people apparently found eccentric, even if just on a temporary basis, I did turn the sound of my light sabre off so as not to interfere with the music. It is also worth noting that while O'Connell describes eccentric behaviour as out of the ordinary behaviour people feel the need to engage in, she does not distinguish those who voluntarily engage in eccentric behaviour due to a strong personal desire to do so, such as an overriding sense of identity (as was the case with my temporarily dressing as a Jedi), and those who engage in eccentric behaviour involuntarily, i.e. are compelled to do so even though they do not wish to. Though an extensive discussion of the nature of voluntary vs involuntary behaviour would be out of place here, it is perhaps enough to note that a person who wears an odd hat because they feel it to be an integral part of their personal self-image and doesn't care what others think, is in a vastly different position to a paranoid person who is quite aware that wearing a tinfoil hat makes them appear odd to others, but is too afraid to go about without it due to an overwhelming fear caused by their mental illness, indeed in the cases of many paranoid people it might be that they are directly incapable of apprehending or correctly evaluating the feelings of others in respect to their behaviour at all.

The subject of "disabled identity" in general has become something of a major one in recent discourse, both in the public and academic spheres.

In 2013, Curwood[221] conducted an extensive survey of young adult literature with respect to the representation of disability. Curwood argues that it is important that younger

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[221]Curwood, J. S. (2013). "Redefining normal: A critical analysis of (dis) ability in young adult literature". *Children's Literature in Education*, 44(1), pp15-28

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

adults are introduced to positive portrayals of "disabled identity", and recommends several works of literature on this subject. This is a project I do initially have sympathy for, particularly given the work I myself have done as staff reviewer on the site "fantasybookreview.co.uk", a site devoted to works of speculative fiction where naturally I take a specific interest in authors' portrayal of disabled characters.

What is interesting to note about Curwood's project however, is that he rigorously contrasts the idea of "disabled identity" as opposed to "normal" or "able" identity, and those five works he recommends are all themed around the idea of a disabled young person achieving their goals and triumphing despite the prejudices of others, often affirming their own selfhood along the way.

I find it significant however that all of these protagonists firstly possess disabilities which have an identifiable social group attached to them such as autism or deafness, and also tend to not affect a person's physical appearance. It is also notable that most of the "obstacles" which the protagonists of such works contend with are therefore social in nature, for example a deaf girl who becomes a band manager whose father refuses to learn sign language, or an autistic boy whose thought processes and modes of behaviour cause problems with relating to colleagues and the established procedures during his time working at a law firm.

As I noted in the conclusion to this work, identification with a specific community, (such as identifying as part of the deaf community), and the problems associated with disability are not necessarily identical, and literature that attempts to pretend the two of them are and thus form a "positive disabled identity" based on an individual's conscious identification with a specific community seems to be side stepping much of what actual disabled experience involves, after all, much of the experience of disability, such as my pouring a glass of water at home is not based on prejudice or social expectations or "triumphing over adversity" it is often just experiencing the direct, simple and quite literal frustration of desires. Any work attempting to represent "disabled experience" (if such a unified animal could be said to exist at all), that does not cover this fact is at the least misleading, if not actively detrimental to public perception due to minimising the real impact that a disability has on a person's life.

This is particularly true in cases where the disability itself manifests on an individual basis, for instance the autistic, animal loving son of a friend of mine was denied a school trip to a zoo because it was held to be against his interests as "an autistic person" to go into a crowded environment by the school authorities, irrespective of either his love of animals or measures he himself could take to control his stress levels in that environment such as wearing earphones, a clear case in which the focus on the boy's "autistic identity" was mistakenly used both to deny his desires, and also deny him equal participation in the school alongside non-disabled children.

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

I have also been aware myself in my interactions with many groups specifically billed as "for the blind" that the emphasis of promoting a radically specific "disabled identity" often has the opposite effect, that of promoting differences and thus increasing the "different human being" paradigm I mentioned in chapter 4, as well as obfuscating the actual issues I encounter in my life. After all it is far more helpful to me if people ask me whether I want to receive reading material in braille or whether it would be helpful for me to do so, rather than automatically assuming that as part of my "blind identity" I demand material in "blind language" something which is directly addressed by Simon Hayhoe in his notes on the inadequacy in responses to provide accessibility for blind people, since only some blind people read braille and of those who do there are occasions when braille is less useful as with the example of my bank's provision of a braille bank statement in chapter 3.

This question of celebrating disabled identity is also addressed quite uniquely by Davis[222] who contrasts the concept of disability with "diversity" as the new alternative to normality. Davis notes that the media is quick to emphasise people's choice of identity whether this be ethnic, racial, gender or even just the choice of product, but that an identity that is enforced by biology, that of being "disabled" is rarely included in this idea of diversity.

This is a unique perspective on the portrayal of disability and its relation to capitalism and one with which I have a distinct personal sympathy, though Davis again however relies upon existing social categorisation which conflates the relationship between how a person is "perceived" and what a person does.

It may be true that I cannot "choose" whether or not to be visually impaired, however as I noted in chapter 4 as a disabled person I can choose my desires and how to fulfil them, in as far as I am competent in dealing with my own disability, can choose how and in what ways to enlist the aid of others to fulfil my desires. Similarly, while I cannot choose how others perceive me (though of course my attitude and abilities can alter that perception), I can choose how important those perceptions of others are to me. If I am performing on stage for instance, I do not care whether the audience perceive me as "Blind" or not. While, as part of my performance I do not usually take my guide dog or other visible mobility aides on stage with me, I equally do not remove my glasses, alter the appearance of my eyes or make any deliberate effort to disguise the fact that I have a visual impairment. My concern when performing is not "do people see me as blind", but "do people see me as a good performer."

This is another reason I believe it is of such major importance to separate the biological limitations upon desire fulfilment caused by any disabling condition, and the social attitudes attached to it, so that the importance of social judgements or any community based identity (such as the deaf community), to which a disabled person might wish to belong to can be separated and considered independently of a person's less favourable life experiences.

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[222]Davis, L. J. "The end of normal". *University of Michigan Press,* (University of Michigan Press, 2013)

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

This separation would also help in actually achieving what Curwood hopes the works of "inspirational literature" would achieve, namely showing the rest of society that having a disability, inconvenient though it often might be, does not fundamentally change the type of human any human is, or the moral, ethical and social status that would be accorded to any human.

Davis continues his analysis by discussing the construction of identity by the liberal media and the concept of diversity replacing that of normality, then uses that concept of disabled identity to discuss ideas such as media portrayal, sexuality and depression. Again however, Davis analysis is so heavily based on an existing cultural construction of what constitutes "disabled" and so completely divorced from actual disabled experience, that frequently his discussion becomes so rarefied as to lose any and all focus, particularly since Davis arguments concern "disability" as a whole and often rest on exclusively generalised assumptions about say, the nature of images or the provenance of media. For example, he spends considerable time discussing how the concept of "the disabled body" fits into post-modernist philosophy, however never once does he actually mention disability stopping a person doing something or having a practical effect on what a person does in theirlife, indeed Davis frequently gave me the strong impression that the "disabled" he speaks of were a mythical species. In this he contrasted markedly with Hayhoe who grounded his more specific examination of the ontology of "blindness" in a detailed historical narrative. Davis even categorically rejects the notion that depression as a form of disability has any significant difference from concepts such as sadness or melancholia, and airily dismisses actual practical discussions of matters such as "insomnia" as some sort of conspiracy by drug companies, despite a note at the beginning of the chapter that he has apparently talked to people with depression. His lackadaisical assertion that "depression did not exist before the 1950's" and his contention that the artistic melancholy of Victorian poets was some sort of pre-diagnoses depression seems simply incorrect according to the actual phenomenology of the experience. After all any person who has suffered depression will recognize literary figures such as Sherlock Holmes, Dr.Manette in Tale of Two Cities or even Conan the Barbarian as suffering it through the basic description of their mental state's debilitating affects despite the fact that all such characters existed before the term "Depression" became one of general medical usage.

Davis constant discussion of "the disabled body" as some strange artefact of a cultural perception so theoretical that it appeared nearly divorced from experience was at a stark contrast to other accounts of the body, and in particular embodied experience such as Carells. Indeed I found myself wondering how exactly the "disabled body" as cultural artefact, a notion which Davis expends considerable theoretical time and effort on actually contrasted to those who have a disabled body, especially when said "disabled body" is not immediately obvious as being disabled as is the case with many conditions from mental illness to dyslexia.

I suspect this focus on "the disabled body" is possibly a rhetorical tool which authors like Davis have borrowed from gender politics, however where having a female or male body

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

is something easily demonstrable as per a set of basic physical characteristics which can be discussed independently of a person's actual gender identity, or yet how the perceptions and expectations of others of those physical characteristics impinge upon that identity; as the "disabled body" is something whose characteristics are far more nebulous and far harder to identify unless one focuses on a tangible quality such as life experience one wonders what "the disabled body" actually is? After all a person with ME (chronic fatigue syndrome), is not disabled as per a definable fact of their physical body which is immediately comprehensible to others, but by a state of their body which impinges directly upon their life experience, energy levels and desires, indeed a chief issue for sufferers of "invisible disabilities" is the very fact that they do not display a visible sign of disability, making it far harder for them to receive assistance or even basic sympathy for their circumstances.

It is also demonstrable as per the intensive epistemological analysis Simon Hayhoe makes of the term "Blindness" and how this differs from other commonly understood disabilities such as mental illness or deafness, that each physical manifestation and group categorisation of disability comes with its own slightly different cultural ontology, ontologies which do not seem easily reduced to a singular category of embodied experience or even cultural perception.

Even as far as the basic so called "visible" disabilities go, there seems to be a qualitative difference in the type of experience involved in a paraplegic wishing to see "people like them" depicted in the media, and their need to make all the complex arrangements necessary to catch a train as per my example in chapter one, qualitative differences which cannot be exemplified by the simple notion of "having a disabled body". I believe here authors such as Davis might be making a category mistake based upon their perception of the conflict between the medical model and the social model, confusing a "diagnosis" of disability with the immediate social and cultural "perception" of disability, both of which have a tangential relationship to the actual lived experience of possessing a disability.

It is with reference to discussions such as Davis' that I see a desire based definition of disability having a major advantage in focusing academic discourse by allowing a practical and realistic examination of the experiences of disabled people, and the ways in which the lives of disabled people can be improved in basic and fundamental ways since, (as I observed in chapter 3), questions of accessibility, effort, assistance, and the conditions of fulfilled desires tend to be central to life with a disability, indeed in many ways far more than the notions of "A disabled body as cultural artefact".

Separating out the idea of disability as the biological prohibition of desire fulfilment would also have the advantage of allowing discussions about concepts such as "depiction of disability in the media" to be far more narrowly focused on the issue at hand. For example, while I fully agree with Davis conclusion that narratives of disabled people in the media tend to show disability as the main defining character trait of any character, and usually are either

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

forcibly inspirational or tragic (though as a disabled performer myself I strongly disagree with his complex and rather unfalsifiable account of why disabled people must be played by able-bodied actors). It would be far better if we asked for fiction to pay more attention to real people and the problems they encounter in life, disability included, than to ask for some sort of token representation of some disabilities. After all a complex character with loves, desires and experiences all their own who equally happens to be disabled is a generally better representation in fiction than simply an endless bundle of positive character traits and sound bites sitting in a wheel chair. Though I disagreed with the rather convoluted way he approached the subject, I did agree with Davis conclusion that having disability simply be "present" without being a focus of any specifically intentioned depiction would be an extremely good thing, in my capacity as a book reviewer I do note such instances on the sadly rare occasions they do occur within speculative fiction.

A definition of disability based on desire fulfilment which allowed for the separate discussion of the cultural perception of disability would also allow comparisons between depictions of different forms of disability. For example I often myself find it disheartening that while authors such as Davis are eager for a "positive portrayal of disability" this portrayal (as those works sighted by Curwood shows), often restricted to very specific types of disabilities such as autism, deafness or paraplegia, and blindness, along with many other physical and temporal impairments, remains something of an afterthought at best.

This is where historical analyses of the epistemological status of various disabilities of the type Hayhoe has provided for blindness would prove helpful, especially if such could be made to highlight the ways in which the cultural construction of various forms of disabilities have contributed to the perception of people with those disabilities as radically different and "special" forms of human being.

Obviously in this thesis I have focused heavily upon the satisfaction of desire as an essential ethical principle. This is similar to the treatment given to freedom by Amartia Sen in his 2013 article concerning sustainability[223]. Sen details the Brundellant report on sustainability which defines sustainability as a state where the needs of the current members of society are met without compromising the needs of future generations, and that the most expedient way of achieving this is focusing resources on the "poor" of each generation. Sen argues however, that while this model's focus on the poor is both admiral and necessary on a global level concerning matters such as environmentalism and population growth, in its characterisation of humans as simply foci of individual needs which can be satisfied via resources, it misses both a fundamental aspect of human experience, and one which itself contributes to promoting overall sustainability.

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[223]Sen, A. (2013). "The ends and means of sustainability". *Journal of Human Development and Capabilities*, 14(1), pp6-20

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

Sen argues that freedom rather than need should be the basis of any macro discussion of long term sustainability and that ultimately the promotion of the maximization of human freedom will itself lead to a net increase in that freedom, as well as a decrease in factors such as resource consumption and population growth. He illustrates this by an appeal to reason as a chief defining factor in determining human freedom itself, and supports his argument by showing direct correlations between the level of women's education and literacy in third world countries, with an increase in women's power and autonomy and subsequent decrease in population growth. He therefore argues that thinking of people as having a basic patient relationship to needs is damaging to sustainability, and rather we should consider human populations as agents in determining their own freedom. He also uses this stance to repudiate hard line social controls or compulsions upon populations to decrease consumption, and indeed speculates that shared property rights and a greater freedom in the ownership of the means of producing resources would result in a decrease in consumption and a beneficial status for the environment.

There is a lot which is appealing in Sen's analyses. In particular the notion that people, even on the country wide level populations should be treated as agents rather than patients, and that the maximization of freedom could also lead to a greater prevalence of freedom, a hypothesis which supports the definition of disability as based upon desires. After all, if a public building had ramps, this would not only allow paraplegic people to enter, but also offer an alternative method of ingress to people who might not wish to use the stairs, e.g. people with walking problems. In addition, in allowing access to paraplegic people to the building, it is trivially true that paraplegic people then have the choice to enter the building or not, for example to attend or not attend a play in a theatre and thereby over all greater cultural visibility and so avoid contributing to damaging stereotypes which in turn aid the overall position of paraplegic people in the future.

It is also significant that Sen directly equates reason and education with the maximization of freedom, indeed this is similar both to Griffin's concept of second order desires, and the problems which frequently occur with disabled people having the fulfilment conditions for desire determined by others that I outlined in chapter 3.

One problem I do have with Sen's analyses, is that while his model of freedom might serve as a way of maximizing sustainability, at the same time it appears to miss a fundamental factor about the nature of human suffering and power.

Sen speaks of "freedom from hunger" and "freedom from ill health" as basic freedoms and notes the importance of promoting these to people who do not have them, however it seems needlessly convoluted to couch what are very basic types of human suffering in the language of freedom, since it seems there is far more to the actual experience of hunger than merely the static recognition of a lack of nourishment, nor would a person who is starving simply note their starvation like a decreasing stat counter in a computer game. This is because humans suffer. A person who is starving is not merely lacking, they are

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

enduring a tangible state of pain and also, eventually, a direct risk of death. Therefore, efforts to alleviate the hunger of a population take on far more significance than simply the gross allocation of resources. Alleviating hunger, even on a macro-analytical level is a uniquely ethical goal and end in itself. Of course, in Sen's context of simply providing a critique of sustainability this probably does not matter; although it probably would in the practical application of Sen's principles, however the question of suffering is a fundamental one in disability.

Just like hunger, unfulfilled desire may be seen as a direct source of suffering and one I have tried to highlight in this thesis, indeed as I previously noted it is frequently unfulfilled desire that provides the most fundamental critiques of basic cultural assumptions concerning disabilities. Disability therefore represents not only a set of assumptions, medical diagnoses or even specific virtues, it represents a source of suffering, through increased effort, through prohibited desires, even directly through restricting freedom as to what types of desires or life choices may be possible. Thus I would argue that while Sen's freedom based approach to sustainability provides some exceptional ways of examining disability on a macro and societal level, and perhaps theoretical principles for matters concerning resource and provision of assistance, at the same time it is not merely the promotion of freedom, but decreasing of the suffering humans feel through the restriction of freedom which should be the goal of such a model. So, it is not merely enough to provide a disabled person with accessible transport that fulfills their desire to get somewhere, but that transport be available according to the wishes and life choices of the disabled person who uses it.

Unfortunately, another point mentioned by Sen is the notion of power, and the fact that increasing the amount of power in decision making for those with restricted freedom promotes greater freedom. Here, Hayhoe's epistemological analyses shows up some major problems with the way that disability and power are discussed, since as long as the discourse on disability remains bound by cultural perceptions tied to intrinsically flawed historical notions, it is open to misconstruction and the depredations of self-interest. This indeed is one reason for my suggestion of the creation of "experts" in disability mentioned in chapter 4 as an attempt to directly equalize the power relation of disabled people, and why I attempted to create an alternative schema for understanding human and animal assistants which (like Sen's contention about sustainability), did not denigrate people to the status of patient.

As articles such as Liasidou's show, with an increasing focus on partisan politics and the radical separation of groups of human experience into separate camps, it seems that the need for a desire based definition of disability is greater than ever. Though discussion concerning disability has certainly progressed, it has not yet managed to overcome the intrinsic problems with the purely social model, or yet provide anything more than rarified notions divorced entirely from the practical experience of disability to combat these problems, and yet as ever more detailed critiques of the currently flawed cultural construction of disabilities show, a conception of what "disability" means, of how the "challenges" of

Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

By Luke Hewitt

living in the world as a disabled person may be conceived, and of the ways in which any disabling condition causes human suffering is now more necessary than ever.

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Disability, Desire and Society: The Establishment of a New, Individualistic Definition of Disability and its Practical Uses in Everyday Life

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