

Transableism, disability and paternalism in public health ethics: taxonomies, identity disorders and persistent unexplained physical symptoms

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Abstract: Transableism is a term which refers to moving between states of being able and disabled by choice rather than by happenstance. Insofar as this may imply a choice to become dependent, claims upon the healthcare system are likely to result. In this piece we aim to explore some ethical and legal implications of such claims. In order to do so, we draw upon current debates over the place of autonomy, beneficence and paternalism in public health ethics, the taxonomy of disability and the status of persistent unexplained physical symptoms (henceforth, PUPS). We suggest that transableism represents a useful construct which may contribute towards resolution of ongoing difficulties within public health ethics and theories of disability. In addition, we believe that it holds promise for the understanding of a significant proportion of patients presenting PUPS. We focus upon identity disorders, particularly in relation to what is currently termed Body Integrity Identity Disorder (henceforth, BIID), where sufferers report a subjective conviction that one or more of their limbs are superfluous, requesting medical assistance to remove the offending limb[s], repair the results of attempts at their self-removal or to provide prostheses and other assistance after removal. We have considered BIID elsewhere in relation to consent, capacity and the doctor/patient relationship (Mackenzie and Cox, 2005). One of us has also explored how the definition of addiction as a chronic relapsing disease within public health governance enables cycles of transitions between the rigours of rational liberal citizenship and the shriven status of the sick (Mackenzie, 2006). Since a central aim in this piece is evaluate the place of transableism within public health ethics, we will begin by considering the latter as a discursive context for the arguments which follow.

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Autonomy, choice and claims upon healthcare resources

Much debate today over healthcare ethics focuses upon scope and language. While the traditional emphasis of medical ethics has been upon the doctor/patient relationship, that of public health is upon whole populations, either national or global. Consequently, while these fields may deploy identical ethical terms, the ways in which these will apply are likely to differ. While the history of the doctor/patient relationship has often been read as a successful battle for patient autonomy as against medical paternalism couched as beneficence, attempts to contain autonomy's paramountcy are being mounted increasingly today, both within clinical care and public health arenas. For instance, Brazier characterises her recent effort to accomplish the dethroning of what she terms the great god Autonomy in order to suggest that patients should bear responsibilities as well as rights as an attempt to maintain medical integrity in the face of moves towards a medical consumerism which threatens to reduce clinicians to body technicians (Brazier, 2006). Similarly, it has been argued that the lawful or obligatory exercise of power and deployment of resources to maximise health may be incompatible with strong patient autonomy: as many public health measures must of necessity be uniform and compulsory, autonomy is an inappropriate guiding principle (O'Neill, 2002a). To an extent, such differences reflect and sustain wider ethicopolitical choices between policies based upon welfare liberalism, traditional communitarianism and radical libertarianism (Hayry, 2005). How these should impact upon public health and clinical care is unclear. Certainly each perspective will favour a specific variant of the doctor/patient relationship. Brazier and O'Neill's emphasis upon trust and beneficence as opposed to autonomy may be seen as promoting communitarianism, as may Stirrat and Gill's suggestion that the doctor/patient relationship be seen as a covenant (Brazier, 2006; O'Neill, 2002b; Stirrat and Gill, 2005).

Where the role of autonomy, beneficence and paternalism in public health ethics is concerned, it is important to distinguish between the elements associated with public health initiatives. The constraining of citizen autonomy associated with public health powers to restrain and quarantine those with infectious disease may rest uneasily beside the human rights based temper of our times, yet few would regard them as unjustifiable. However, the censuring of lifestyle choices associated with deleterious health consequences appears to many as moralising couched in medical terms. As Smith puts it, the 'frequent concordance of morality and what passes at any particular time as the science of public health must surely be more than coincidence' (Smith, 2001, p. 329). Public health taxonomies, such as those which have created obesity as an epidemic of chronic disease, with dire implications for future health status, depleting scarce healthcare resources and the result of sloth and greed, do so on a basis of suspect science (Gard and Wright, 2005). Consequently, attempts to allocate healthcare preferentially to the deserving unwell, such as the recent National Institute of Clinical Excellence guidelines on IVF treatment for the obese, while they may be couched in terms of probabilistic clinical outcomes, arouse unease. Indeed, NICE's 2005 guidelines on self-inflicted harm have been condemned as incoherent (Holm, 2006). Autonomy and beneficence in this context take on more contested meanings, as do taxonomies of health and ill health (Mackenzie, 2006).

Transableism represents a nexus for these concerns. Public health promotion campaigns which seek to persuade us to eschew excessive indulgence in pleasures which may result in ill health have generally failed to persuade us to do so. In part, this is caused by a general response of healthy scepticism. Many of us fail to be convinced that our lifestyle choices are seriously harmful, nor that their possible health consequences should affect our entitlement to healthcare subsequently. Yet where the harm and the consequences are unequivocal, and result from autonomous choice, many agree that ideas of desert colour the usual assumption that healthcare should be provided according to need. In the United Kingdom recently, the allocation of a second liver to George Best, a famous alcoholic ex-football star who continued to consume alcohol, and eventually died from the failure of his second liver, aroused wide public condemnation. Those who choose to engage on behaviours which will undoubtedly result in ill health, consuming healthcare resources thereby, may be seen as harming others as well as themselves. The resources necessary to provide me with my second liver may mean your baby, who is born prematurely, dies because the facilities necessary to keep her alive cannot be funded. Does this mean I must take on an obligation to eschew alcohol if I am to receive a second liver? These ethical issues are rendered more complex as treatments which remedy excess become available. Sulphasalazine, a drug which may heal the liver of chronic alcoholics, is about to begin clinical trials in the United Kingdom, while other pharmaceuticals promise the prospect of maintaining a healthy weight and muscle tone despite overindulgence (Templeton, 2006). If I pay for my own Sulphasalazine, and continue to consume excess alcohol, whom do I harm? Should I be required to fund my own medical treatment for the consequences of my choices in this way? And, if so, on what grounds?

The issues traversed so far demonstrate that, to an extent, these debates reduce to choices over where and how to assign obligations to provide healthcare resources, and justifications for refusing

them. Mirroring these concerns are questions over how far patients might be expected to assume commensurate obligations and of what these might consist. For example, public health preventative campaigns might be read as constructing a duty to be well. Measures of harm may then reduce to estimates of how far one places demands which result from previous choices upon healthcare resources. The relationship between the place of paternalism within public health ethics and theories of disability will now be explored in this light, in order to provide a theoretical context for our model of transableism. We have chosen to focus upon BIID and PUPS as illustrations of how the term transableism may help to understand a significant proportion of claims made on the public healthcare system and where the limits of paternalism might lie in relation to these.

Beneficence, autonomy and paternalism in public health ethics

Taxonomic boundaries between health, ill health and disability are fluid and contested, especially when these intersect with notions of choice, need and claims on healthcare resources (Biggs and Mackenzie, 2000). Public health both creates and polices these definitions. How far citizens should be able to make claims to healthcare resources on the basis of clinical need, and how far their lifestyle choices should affect their entitlement, is partially determined by public health taxonomies of health, ill health and disability. For instance, a very fat person may be condemned as having exercised inappropriate lifestyle choices and be denied IVF until they lose weight, or be diagnosed as morbidly obese and offered gut stapling surgery, or be allocated special assistance on grounds of disability. Contingent policies over the relationship between autonomy and paternalism within public health underpin this categorisation process. Adjudication here is complex. Public health goals of producing benefits, reducing or preventing harms and maximising utility in healthcare are unlikely to be completely compatible with principles familiar within medical ethics. In addition, views on the place of protective paternalism within public health vary (Grill and Hansson, 2005). Childress et al. have proposed five ‘justificatory conditions’ which may resolve conflicts among such general moral considerations in public health ethics: effectiveness, proportionality, necessity, least infringement and public justification (Childress et al., 2002). Nonetheless, these means fail to resolve issues surrounding the acceptability of paternalism where an individual’s actions are voluntary and selfregarding (i.e. likely to affect adversely that individual alone) rather than other-regarding (i.e. adverse consequences are likely to affect others primarily). Childress et al. characterise this sense of paternalism as morally interesting and problematic. It is this aspect of paternalism within public health ethics which we wish to consider briefly now in relation to our subsequent exploration of transableism. Paternalism is not inherently unjustifiable. Weak or soft paternalism is accepted as appropriate in cases involving protection of those engaged in non-voluntary self-regarding practices, and may indeed be welcomed by those in dependent positions interpreting it as beneficence. Paternalistic practices may also be helpfully employed to maximise the autonomy of those in positions of dependence who possess less than full autonomy, as exemplified in s. 4(4) of the Mental Capacity Act 2005. Yet strong or hard paternalistic coercive interventions into voluntary self-regarding conduct would, according to Childress et al:

‘be insulting and disrespectful to individuals because it would override their voluntary actions for their own benefit, even though their actions do not harm others. Such actions are thus very difficult to justify in a liberal, pluralistic democracy.’ (Childress et al., p. 176)

Ethical inquiry into justifiable limitations on paternalism must then focus on degrees of voluntariness in individuals’ decisions and the extent to which their conduct can be said to harm others. Childress et al. make the salient point that, when calculating harm, including many elements such as financial and emotional costs to society ‘can appear to make virtually any intervention nonpaternalistic’, but that the central ethical issue is whether the significance of the costs justifies the intervention (Childress et al., p.176). In our view, these costs are particularly difficult to assess where those making a claim upon healthcare resources do so from dependent positions which fall outside current diagnostic categories. In addition, where such dependence may arise from choice, how far paternalistic intervention may be justified is contentious. The remainder of this article will explore these difficulties in relation to transableism, identity disorders located in the body and PUPS, first drawing upon theories of disability and recent advances in neuroscience.

Public health ethics and theories of disability

Many criticise policies for the disabled as insufficiently examined, reductionist and stigmatising (Danermark and Gellerstedt, 2004; Goodlad and Riddell, 2005; Silver, 1998, 2003). Such commentators argue that policies designed to promote social justice have been tainted, and the citizenship of those with physical impairments compromised (Danermark and Gellerstedt, 2004; Goodlad and Riddell, 2005). The validity of varying concepts of disability is central here. Critics of the medico-individualist deficit model, wherein a person is seen as having a disability in the field of health, employment or education which must be corrected, have asserted that the terms normal and abnormal embody social

judgements which distinguish between acceptable and unacceptable biological variations and levels of functioning (Amundsen, 2000). The strategies of identity politics have supported a social model of disability as an identity imposed upon the basis of physical impairment. This has sustained a politics of resistance which moves away from the typology of disability as a personal tragedy towards a model framing it a form of social exclusion (Hughes and Paterson, 1997). Recently, however, oppositions between the presence and absence of disability have been condemned as an overly essentialist strategy obscuring the diversity of voices within the many cultural factors associated with disability (Corker and Shakespeare, 2002). Listening to these voices is seen as a means of recognising difference and diversity within and amongst cultures which enables the formulation of alternative truths moving beyond the association of disability and disadvantage (Clapton, 2003; Silver, 2003). These theoretical portrayals of disability have played a part in public health ethics principally within the debates over the morality of reproductive choice in relation to genetic conditions. These have been shaped by ideas of impairment versus disability, along with the three models of disability as a biomedical condition causing disadvantage, a socially created label of disabled superimposed on impairment and a discursively constructed notion of disability allowing for the possibility of resistance through a recognition of diversity and difference. Disagreements over conceptions of ‘normal’ and the politics of normalisation continue.

This impacts on the subject matter of this article in that public health policies rely upon evidence bases derived from epidemiological investigations. The state’s interest in the health of its citizenry has a particular resonance for public health ethics, since the characteristics of any population will be categorised, statistically, as either normal or abnormal. While there is no necessary connection between a quality which falls either inside or outside a statistical norm and that quality’s being assigned normative value, slippage between the two happens, and gives rise to concern. The term ‘abnormal’ has acquired pejorative force. In addition, within the health lexicon, it suggests a condition in need of a remedy, treatment or cure so that it might fit within the norm. Ethical issues arise as a result of this linguistic imperative that the abnormal should be subjected to normalisation. As public health methodology is aetiological and its orientation preventative and remedial, it seems plausible that it would prove particularly vulnerable to presumptions of normalisation as a built-in moral hazard where slippage takes place. The biomedical conception of disability espoused within public health policies means that conditions which may be experienced subjectively as embodying difference and diversity are more likely to be officially envisaged as disabilities in need of prevention or remedy. Those seeking to theorise disability have engaged with the difficulties which this orientation is likely to cause for those who might wish to preserve their differences rather than have them labeled as disabilities and subjected to blanket medical treatments. Silvers distinguishes between disability and ill health in order to condemn the coercion involved in the normalising strategies of public health initiatives which seek to render the different as close as possible to the ‘normal’ (Silvers 1998, 2003). Clapton argues that medical ethics constructs the human good in such a way as to marginalise those with disabilities as ‘inferior others’ (Clapton, 2003). Others cite examples of amputees who would prefer wheelchairs to prosthetic legs which render movement more unstable, along with those born with different limbs as a result of thalidomide who would have wished to retain them rather than have them amputated and replaced with prostheses, and those in deaf communities who have no desire for hearing aids for themselves or for cochlear implants for their children (Danermark and Gellstedt, 2004; Silvers, 1998, 2003). In similar vein, many of those born intersex who were provided with approximations of male or female genitalia have subsequently expressed the wish that they had been accepted as different rather than condemned as abnormal and subjected to surgical normalisation in childhood.

This emphasis on the acceptance of difference and diversity has ethical implications for how public health should treat disability. If people with disabilities are not to be perceived as having a unifying group identity, means of ensuring social justice do not hinge simply upon remedial medical treatment and prevention but more broadly upon inculcating means by which parity of participation in civic life might be ensured. There is a growing consensus that dialogues involving individual narratives, counter-truths and parrhesias, or risky truths, offer the most promise here (Clapton, 2003; Corker and Shakespeare, 2002; Danermark and Gellstedt, 2004; Hughes and Paterson, 1997; Meekosha 2004; Silvers, 1998, 2003). Silvers promotes the strategy of working towards a neutral conception of disability, arguing that disability is an essentially contested concept. As a consequence, she favours dialogue leading towards a ‘neutral account of disability [which] will ground rehabilitation strategies in a sensible and sensitive paradigm of the relation between a functionally diverse citizenry and an inclusive state’ (Silvers, 2003, p. 485).

Within such a model, distinctions between disability, dependence and ill health are crucial. The inclusive state has an obligation to citizens suffering from impairments to provide means by which their ability to participate in civic life might be fostered. In other words, dependence which results from impairment is to be transformed into independence or autonomy. Those suffering from ill health have a different claim on the state, that of healthcare ideally leading to a cure, or, where this is not possible, to support for their dependent state. The provision of healthcare for chronic conditions,

then, assumes that a degree of patient dependence is inevitable, not only because this is inherent in the doctor/patient relationship but also in that less can be expected of us when we are ill. Once we have the identity of a person with a long-term illness, we have a claim to medical attention, comfort care and acceptance of our dependent state. Here, then, paternalistic support is accepted, welcomed and provided as of right. Yet public health policies seeking to minimise dependence resulting from disability and ill health are contentious. State provision of technology allowing reproductive choices to prevent disabled children from being born has been both condemned as covert eugenics and acclaimed as promoting reproductive autonomy. In similar vein, public health campaign exhortations to eschew smoking, drinking alcohol, eating salty and fatty foods and pursuing sedentary lifestyles may be viewed as appropriate promotion of responsible autonomy or the overly paternalistic (or maternalistic) interventions of the nanny state.

The rest of this article will introduce transableism, then explore how this might impact upon the proposed neutral account of disability in order to consider how this might relate to an appropriate role for paternalism within public health ethics. Recent advances in neuroscience which affect ideas of voluntariness and bodily located identity disorders will be drawn upon.

Transableism: amputees, devotees and wannabes

Transableism is a term which refers to moving between states of being able bodied and disabled by choice rather than happenstance. Outside a neutral conception of disability, then, it may imply a choice to become dependent. Its linguistic genealogy is uncertain. We have been working with the concept for some time. However, claims to have invented it have also been put forward by paradevo, the operator of a website, <http://www.transabled.org>, which caters for those wishing to share their thoughts and experiences about the process of moving amongst different degrees and types of able bodiedness and those involved in this. Paradevo makes an explicit comparison between transableists and the transgendered, or transsexuals, i.e. those who undertake hormonal or surgical treatment in order to move between genders after being diagnosed as suffering from Gender Identity Disorder, or GID. While the latter have found social and medical acceptance, the former have not. Specific terms to describe those involved in internet groups such as <http://www.transabled.com> have arisen. Devotees are those who are erotically attracted to specific characteristics of those who are not able bodied, while wannabes are the able bodied who wish to transform themselves into the disabled, whether via self-demand amputation, deliberately induced paralysis or other forms of bodily alteration generally regarded as self-harm. Researchers who have published in this area usually focus upon those who wish to have limbs amputated, who are often seen as suffering from a medical condition termed Body Integrity Identity Disorder, or BIID (Bayne and Levy, 2005; Berger, 2005; First, 2005; Furth, 2000; Johnston and Elliott, 2002; Jordan, 2004). However, this condition does not appear in the current edition of the Diagnostic and Statistical Manual for Mental Disorders, DSM-IV, and may not be seen as meeting the criteria for that due out in 2010. Ethical debate has centred upon balancing the right of those requesting amputations to make autonomous decisions about their own bodies with doctors' responsibilities to their patients to alleviate suffering and provide appropriate treatment. At issue has been the question of whether amputating a healthy limb can be seen in this light. Within a legal frame, this translates as an interrogation of the limits of autonomous consent in relation to harm (Johnston and Elliott, 2002). In addition, the parameters of the doctor's duty of care come into question: these are defined by the presence of a responsible body of opinion, or professional guidelines, on disorders recognised as medical conditions with a range of acceptable treatments. This is not the case with BIID, where the paucity of cases, the anecdotal nature of the assurances that amputation provides a permanent alleviation of suffering and the reliance upon the testimony of support groups on the internet taken together render the safeguards of evidence based clinical practice impossible to obtain. As a consequence, doctors who wish to accede to a request to amputate a healthy limb in order to relieve suffering, even where patients are able to produce evidence from psychiatrists that they are not mentally disordered, and have undergone other forms of treatment without success, are placing themselves in professional peril should they proceed with the operation. As we have written on this topic elsewhere, we do not propose to do anything other than provide this sketchy account of issues surrounding treatment for BIID (Mackenzie and Cox, 2005). Instead, we now wish to consider how recent developments in neuroscience might impact on voluntariness and hence the appropriate limits of paternalism in public health ethics.

Neuroscience, voluntariness and paternalism

For a decision to be voluntary, it must be made by a person from a position of autonomy, or, in legal terms, competence. This implies that the decision should be made freely: while it might be irrational, provided it has not been improperly influenced by another, or undermined by incapacity, an autonomous choice should be respected. Nonetheless, the relationship between judgements that a specific decision is irrational and the classification of the person making the decision as lacking the capacity to make an autonomous decision is clearly a vexed one. One of the issues here is the relationship between autonomy and aetiology. Where, say, a person refuses to eat, considering

themselves to be too fat, a diagnosis of anorexia may be made and compulsory feeding may take place lawfully as treatment for what is seen as a mental disorder, anorexia. The refusal of treatment [food] may be seen as able to be overridden as it is not a sign of autonomy but a symptom of the mental disorder anorexia. Yet the lack of an accepted causative mechanism for anorexia, along with the gloomy prognosis even where force feeding takes place, creates a feeling of unease where an allegation that incapacity caused by anorexia justifies the overriding of a decision not to eat, however irrational such a decision may appear to be.

The desire to amend bodily form associated with a complex of conditions known as identity disorders raises similar ethical issues over voluntariness. While the medical profession is now routinely involved in a gatekeeping role regulating access to gender reassignment procedures for those diagnosed as suffering from GID, how far this should be seen as a medical or mental disorder has remained a contested question for nearly half a century. Both GID and BIID are associated with groups of patients who claim medical treatment involving surgery on the grounds that their identities, or their subjective views of their authentic selves, do not conform with their bodies as they are presently constituted. Surgical intervention may be justified on the basis that the degree of suffering associated with such fixed beliefs over identity cannot be relieved otherwise, since medication and cognitive behavioural therapy have proven largely unsuccessful in doing so. Hence the fact that the beliefs and suffering remain unamenable to persuasion underpins the classification of a form of identity disorder. Yet as the aetiology of these disorders remains contentious, the status of the request for medical intervention to support a fixed notion of subjective identity is uncertain.

Recent advances in neuroscience appear to offer some promise here. Studies have demonstrated that our brains contain neurally based 'body schema', or representations of our bodies. These impact on what have been seen in terms of identity disorders, body dysmorphia and anorexia in that each of these is implicated in subjective perceptions of the body which do not conform with those found in inter-subjective reality. In other words, those with identity disorders do not perceive themselves as being 'really' the person of a particular gender, or with the complement of limbs, with which they were born; those with body dysmorphia consider parts of their body to be intolerably diseased or unattractive and those with anorexia perceive themselves as too fat, even when they are dangerously thin. Ehrsson et al. have carried out a series of experiments which suggest that the body schema mapped in the brain is generated by the parietal cortex, and that when the functioning of this area is disrupted, distortions in subjective perceptions of body shape and size result (Ehrsson et al., 2005a). In Ehrsson's view, this 'supports the idea that our brains compute our body size by integrating signals from the skin, muscles and joints, as well as visual cues' (Ravilious, 2005). His team hopes that their research may lead to treatments for disorders such as anorexia.

In addition, associated research carried out by Ehrsson et al. suggests that the parietal cortex is involved in the sense that one's body, or parts of one's body, are part of oneself (Ehrsson et al., 2005b). Ehrsson et al. describe these results as supporting the hypothesis that the detection of correlated multi-sensory signals by the pre-motor, intraparietal and cerebellar regions provides the mechanism for feelings of body ownership. Hence an artificially induced integration of visual, tactile and proprioceptive information may give rise to the feeling that an artificial limb is part of our body. Thus, in some cases, neural correlation of intersensory input takes place in such a way as to make patterns which result in illusions which are experienced subjectively as real. This suggests that those who are diagnosed as suffering from identity disorders on the basis of subjective experiences of body ownership which do not conform with intersubjective judgements might be categorised by specific characteristics associated with their parietal cortices. In our view, this suggests that BIID and GID may offer potential for future research here.

Yet, should such a connection be evidenced, how this might impact upon considerations of autonomy, voluntariness and paternalism remains contentious. Were a neutral conception of disability to be in place within public health and clinical decision-making, such characteristics might be interpreted as an example of diversity rather than abnormality in a pejorative sense, or abnormality as indicating a need for remediation. Nor would an ability to specify such characteristics necessarily imply a means to alter them. Nonetheless, where these hypothetical characteristics of the parietal cortex led to requests for surgical intervention, as in the amputation of a healthy limb or gender reassignment surgery, how voluntary might such requests be thought to be? Where subjective perceptions differ from those commonly accepted within intersubjective reality, attempts to anchor the perceptions in specific mechanisms or locations in the brain are liable to be condemned as reductionist, or as underestimating neural plasticity. In addition, invalidation of such subjective perceptions may be seen as unjustifiably reliant upon epistemological externalism. These issues may be sidelined to an extent where there has been damage to the brain, resulting in perceptual and behavioural manifestations, and all three variables are capable of being measured. Anderson and Lux have evaluated the impact of specific frontal brain injuries on behaviour and subjective perceptions in order to assert that 'one's autonomy is diminished to the extent to which one's ability to assess one's capacities is impaired . . . inaccurate self assessment

undermines the extent to which an action is one's own' (Anderson and Lux, 2004a, pp. 282–4). As the anterior brain regions are involved in the executive function of integrating information so that feedback mechanisms enable coherent, structured, adaptive and goal directed actions, Anderson and Lux suggest that 'there is some degree of isomorphism between autonomy and executive function, in that deficits in executive function seem to correspond directly and closely with loss of autonomy' (Anderson and Lux, 2004a, p. 288; 2004b).

While Anderson and Lux do not consider the characteristics of the parietal cortex which in our view the research of the two teams led by Ehrsson suggests may contribute towards BIID and GID, their assertions rest upon observations of a neurologically induced general cognitive rigidity and incapacity to incorporate new information in a way which permits adaptation to perceptions of intersubjective reality. The fact that cognitive behavioural therapy and anti-psychotic medication have proven ineffectual in relation to similar subjective perceptions of identity in BIID and GID would tend to support our hypothesis that unidentified neurocognitive characteristics involving parietal cortex integration of subjective perceptions of body ownership and morphology are involved in the aetiology of these conditions.

How might this relate to the place of paternalism and notions of disability within public health ethics where those with BIID request surgical intervention to amputate a healthy limb which is experienced subjectively as superfluous? According to the criteria suggested by Childress et al., ethical evaluation of a paternalistic intervention to prohibit amputation on request taking place would rest upon how voluntary the request might be seen as being, and on whether the significance of the costs to others justified the intervention (Childress et al., 2002). If a neutral conception of disability were to mandate that variations of parietal cortex function were to be interpreted as difference rather than disability, such a request would be unable to be dismissed as lacking in voluntariness because of an invalidating physical origin. In addition, the relationship between transableism and a neutral conception of disability would become salient. Silvers asserts that conceiving disability as normatively neutral places an ethical obligation upon the state to ensure equality of participation to all citizens, irrespective of their degree of ableism (Silvers, 2003). This implies that while means to ensure participatory equality should be available to all, normalisation should take place only where an autonomous request for it is made. A corollary of this is that autonomous decisions to move within varying states of able bodiedness should not be subjected axiomatically to normative condemnation, as a neutral conception of disability implies that transableism should be tolerated. The extent to which it should be enabled, if at all, is a separate ethical question.

Yet how autonomous such requests might be seen as being is not straightforward. Ethical judgements over how far a decision to move from an able bodied to a disabled state can ever be adjudged autonomous rest upon one's conception of how disability relates to autonomy. Where, under a neutral conception of disability, the state is obliged to provide means to remedy any participatory disadvantages associated with a disabled state, it might be thought that disability need not imply dependence, or anything less than full autonomy as conceptualised under John Stuart Mill's liberal model. Yet this claim on state resources comes from an initial starting point of dependence triggered by a state of disability. How far, then, might a decision to move into such a state be seen as autonomous?

According to Mill, one cannot make an autonomous decision to sell oneself into slavery: that is, it is not possible to decide with autonomy to live without autonomy. Indeed, if a patient provides evidence of a wish to relinquish autonomy completely through deliberately choosing to die, either through a refusal of life-saving treatment or an attempt to commit suicide, this precipitates an inquiry into that patient's state of mind. The presumption within healthcare provision, as elsewhere, is that the autonomy of such a decision may be compromised by mental disturbances such as depression. Nonetheless, the possibility that decisions to refuse life-saving treatment or to commit suicide may not involve factors which would invalidate autonomy is recognised in English law. We may, then, autonomously relinquish our autonomy as defined by Mill completely provided we relinquish life at the same time. Nor does reading autonomy in Mill's sense prevent our making an autonomous decision to compromise it. The aging King Lear's decision to hand his daughters their patrimony and to rely upon their good will for his support may have been foolish, but was nonetheless autonomous. Under readings of autonomy as relational, to be human is to be a social being passing through different developmental stages, with mutual reliance, dependence and vulnerability thus rendering autonomy far from absolute in the liberal sense. Yet decisions to become vulnerable to another, or assumptions that another will care for us, usually take place within private rather than civic life, as there is an expectation that in the civic sphere we will wish to be autonomous. Altruism, mutuality and developmental dependencies are framed as contained by the private in this respect. Thus, despite the criticisms of feminists and others of the public/private distinction, while we might make an autonomous decision to compromise our autonomy by placing ourselves in a dependent position, our motives for doing so are likely to be seen as suspect if we then make a claim upon civic resources. Claims to civic care will usually succeed only where the need for it is seen as involuntarily

engendered. In current public health policy this translates into the recent initiatives seeking to restrict the healthcare entitlements of those seen as suffering from self-induced medical conditions, such as those caused by smoking. Taxonomy is crucial here. Where addictions are classified as diseases, an addict's entitlement to healthcare resources is uncompromised by the moral opprobrium which accompanies an alternative classification as evidence of weak character (Mackenzie, 2006). From the latter perspective, the public health paternalism of attempting to prevent self-induced harms to individuals by restricting healthcare associated with those harms is justified upon the grounds that such claims upon limited resources harm others whose healthcare needs are not self-induced by leaving the others with diminished resources. This juxtaposition of self-induced harm with moral unworthiness leads to another kind of slippage where dependence, or a lack of autonomy, associated with choice becomes suspect. A foreseeable consequence of this ethical stance is an increasing medicalisation of dependent states of being otherwise subject to moral condemnation. Many of us would prefer the identity of being ill than that of being a weak or wicked person. In addition, not all of us, for various reasons, wish to be, or are capable of being, autonomous at all times. We may experience a need to be dependent yet be unable to rely upon receiving adequate care in this dependent state in our private lives. Hence, in this context, public health policies which impose the expectation that members of the public will take autonomous responsibility for their health also lead to unforeseen consequences. Dependence upon paternalism as beneficence provided through public health services is fostered. The worried well regard themselves as permanently under threat of ill health, while those who for whatever reason feel unable to manifest the requisite autonomy are tempted to assuage this moral imperative by adopting an identity of dependence legitimated via medicalisation. In what Salmon and Peters have described as a social epidemic, persistent unexplained physical symptoms, or PUPS, may be triggered by a combination of media coverage of symptomology, medical consumerism and the rise of special interest groups, which together act to alter the perception of illness among a group of people who may be made vulnerable by interpersonal factors (Salmon and Peters, 2002). Hence identity disorders may proliferate as the medical profession colludes, albeit reluctantly, to shape these perceptions into legitimate pseudosyndromes by medicalising conditions that consumerism has defined as illness.

Where the appropriate limits upon paternalistic interventions in public health might be in such a melange is a complex moral dilemma. A starting point is the distinction between the strong paternalism which overrides autonomous self-regarding decisions in the best interests of the wider society and that which protects the best interests of the dependent, whose autonomy is compromised. Another is the distinction between disability and ill health. The neutral conception of disability asserts that once impairment is remedied, the disabled will be enabled to participate in civic society from a position of full autonomy. Those suffering from chronic ill health, however, receive ongoing civic care in recognition of their compromised autonomy or dependence. In addition, normative approval or disapproval of choice in relation to movements between able bodied and disabled status, as well as between autonomous and dependent states, comes into question. We are of the view that the term transableism may help to conceptualise the behaviour of various heterogeneous groups of people making claims on the public healthcare system, and where the acceptable limits of paternalism might lie in relation to them. If the public healthcare system is pictured as an umbrella, then the claimants appear to be distributed along five separate axes under its shelter. These are autonomy and dependence, able bodiedness and disability, known and unknown aetiologies, short-term and chronic ill health, and normative approval and disapproval. From the preceding discussion, it will appear self-evident that autonomous claimants with short-term health problems of known aetiology are likely to be associated with the least paternalism and the most normative approval. Commensurately, dependent claimants with chronic health problems of unknown aetiology are likely to be associated with the maximum paternalistic interventions and the least normative approval. The wealth of literature on the management of those with PUPS, often designated by pejorative terms such as heartsink patients, bears out this assertion (Carson et al., 2000; Mayou and Farmer, 2002; Salmon and Peters, 2002; Sharpe, 2002). Under a neutral conception of disability, degrees of able bodiedness would prove irrelevant to degrees of both paternalistic intervention and normative approval, as impairments would ground absolute claims to measures ensuring the ability to engage in civic participation.

Various ethical concerns emerge from this taxonomy. Transableism may involve a desire to experience disability or dependence on a permanent or temporary basis. Those seeking medical assistance for a one-off procedure, such as those with BIID requesting amputation of a healthy limb, fall into a discrete category. According to the limited anecdotal evidence base available, once the amputation has taken place prostheses are adopted successfully, psychic suffering ceases and entrance into fully autonomous lives takes place as subjective and intersubjective notions of identity are congruent. Hence paternalistic intervention to prevent amputation of a healthy limb would appear to be unjustified. The cost to the rest of society of providing the prostheses would be slight compared to the seriousness of overriding a self-regarding action, regardless of whether the aetiology of BIID involves biomedical variation or the wish to have the identity of an amputee. The selfregarding choices many of us make which cause us to make long-term demands upon healthcare

resources, such as those where over-indulgence is implicated, are far more costly in economic terms, but remain immune to paternalistic prohibition. In addition, in simply financial terms, the resources needed to treat the emotional and physical damage caused by sufferers from BIID who attempt unsuccessfully to remove a limb themselves is substantial, as well as highly counterproductive. Yet where transableism involves the choice to assume an identity of dependence, and this is medicalised, as appears to be the case at least some of the time with PUPS, ethical choices over paternalism are more complex. PUPS are a significant public health problem found in all specialities, countries and cultures. A recent report by the Chief Medical Officer estimates their prevalence at 20% of consultations, while research by Carson et al. suggests that 30% of neurology outpatient referrals are for PUPS, with the patients concerned experiencing significant impairment and distress, along with a poor prognosis (Carson et al., 2000; Dept of Health, 2002). An unknown proportion of PUPS may be viewed as an expression of transableism wherein patients use unexplained symptoms as a way of gaining a new identity that produces gain in their lives. We are aware of individuals who have adopted 'disabled identities' in order to swim in disability events and others who have become proficient wheelchair athletes after adopting a convincing life as paraplegics in whom no somatic disease process exists. Furthermore, it could be that the recent exposure of women falsifying their genetic history in order to obtain bilateral mastectomies represents another example of transabled identity seekers (Manchester Evening News, 2005).

Yet transableism read as PUPS need not imply bad faith. Many of those with PUPS are undoubtedly afflicted with biomedical conditions whose aetiology will be ascertained at some time in the future. In addition, medicalisation is one of the very few refuges which allow us to request care and experience dependence outside the private sphere. Those who are unable to access supportive private spheres have every incentive to manifest unhappiness symptomatically, as do those whose spiritual needs for retreat and a sympathetic ear find solace in today's secular society only in the surgeries of bemused general practitioners. The ethical dilemma for public health ethics in this arena is to identify means to foster transabilities which move away from disability and dependence to maximise autonomy and civic participation. These will inevitably involve paternalism in one form or another.

The economic costs for the public health system of transableism and PUPs are high, perhaps sufficiently so to justify paternalistic intervention on the grounds of the cost to others. In our view, such initiatives should take different forms. Where transableism is concerned, the key questions concern not only aetiology but also reversability, and how this may be set in motion. There is an urgent need for an evidence base to establish what spectrum of factors may trigger the need to change identity, bodily form or health practices from abled to non-abled states of being, as well as the reverse journey from dependence to autonomy. Methods to assess a range of paternalistic public health measures are essential if medicine is to help patients move back to ableism, or to foster the autonomy of those experiencing dependence. In addition, if cyclic movements between abled and non-abled states are involved, as may be the case with addiction, insight into the mechanisms involved would prove beneficial (Mackenzie, 2006). It is here that we believe that current theorising of disability may provide a valuable contribution in its emphasis not only on fostering autonomy through a neutral conception of disability, but also upon the need to formulate alternative truths which move beyond the equation of disability, difference and dependence. Listening to the diversity of voices within the many cultural factors associated with transableism and PUPS would, we believe, enable public health paternalism to operate in an ethical and effective manner in this troubled area.

References

- AMUNDSEN, R. (2000) 'Against Normal Function', *Studies in History and Philosophy of Biological and Biomedical Sciences* 31: 33–53.
- ANDERSON, J. and LUX, W. (2004a) 'Knowing Your Own Strength: Accurate Self Assessment as a Requirement For Personal Autonomy', *Philosophy, Psychiatry & Psychology* 11: 279–94.
- ANDERSON, J. and LUX, W. (2004b) 'Accurate Self Assessment, Autonomous Ignorance and the Appreciation of Disability', *Philosophy, Psychiatry & Psychology* 11: 309–12.
- BAYNE, T. and LEVY, N. (2005) 'Amputees by Choice: Body Integrity Identity Disorder and the Ethics of Amputation', *Journal of Applied Philosophy* 22: 75–86.
- BERGER, B. (2005) 'Nonpsychotic, Nonparaphilic Self-amputation and the Internet', *Comprehensive Psychiatry* 46: 380–83.
- BIGGS, Hazel and MACKENZIE, Robin (2000) 'Viagra is Coming! The Rhetoric of Choice and Need', in Michael Freeman and Andrew Lewis, (eds.) *Law and Medicine*. Oxford: Oxford University Press, pp. 341–61.
- BRAZIER, Margaret (2006) 'Do No Harm: Do Patients Have Responsibilities Too?', *Cambridge Law Journal* 65: 397–422.
- BRAZIER, Margaret (2000) 'Does Medical Law Have a Future?' in D. Hart (ed.) *Laws future(s)*. Oxford: Hart Publishing, pp. 371–89.

- CALLAHAN, Daniel and JENNINGS, B (2002) 'Ethics and Public Health: Forging a Strong Relationship', *American Journal of Public Health* 92: 169–76.
- CARSON, A. et al. (2000) 'Do Medically Unexplained Symptoms Matter? A Prospective Cohort Study of 300 New Referrals to Neurology Outpatient Clinics', *Journal of Neurology and Neurosurgical Psychiatry* 68: 207.
- CHILDRESS, J. et al. (2002) 'Public Health Ethics: Mapping the Terrain', *Journal of Law, Medicine and Ethics* 30: 170–78.
- CLAPTON, J. (2003) 'Tragedy and Catastrophe: Contentious Discourses of Ethics and Disability', *Journal of Intellectual Disability Research* 47: 54–55.
- CORKER, M. and SHAKESPEARE, Tom (2002) *Disability/Postmodernity: Embodying Disability Theory*. New York: Continuum.
- DANERMARK, B and GELLERSTEDT, L (2004) 'Social Justice: Redistribution and Recognition – a Nonreductionist Perspective on Disability', *Disability & Society* 19: 339–53.
- Department of Health (2002) *The Chief Medical Officer's Working Group's Report on Chronic Fatigue Syndrome/myalgic Encephalitis*. London: Department of Health.
- EHRSSON, H. et al. (2005a) 'Neural Substrate of Body Size: Illusory Feeling of Shrinking of the Waist', *Public Library of Science Biology* 3: 412–20.
- EHRSSON, H. et al. (2005b) 'Touching a Rubber Hand: Feeling of Body Ownership is Associated with Activity in Multisensory Brain Areas', *Journal of Neuroscience* 25: 10564–73.
- FIRST, M. (2004) 'Desire for the Amputation of a Limb: Paraphilia, Psychosis or a New Type of Identity Disorder', *Psychological Medicine* 35: 919–28.
- FURTH, G. (2000) *Amputee Identity Disorder: Information, Questions, Answers, Recommendations About Selfdemand Amputation*. New York: Authorhouse.
- GARD, M. and WRIGHT, J. (2005) *The Obesity Epidemic: Science, Morality and Ideology*, London: Routledge.
- GOODLAD, R. and RIDDELL, S. (2005) 'Social Justice and Disabled People: Principles and Challenges', *Social Policy & Society* 4: 45–54.
- GRILL, K. and HANSSON, S. (2005) 'Epistemic Paternalism in Public Health', *Journal of Medical Ethics* 31: 648–53.
- HAYRY, M. (2006) 'Public Health and Human Values', *Journal of Medical Ethics* 32: 519–21.
- HOLM, S. (2006) 'Self Inflicted Harm: NICE in Ethical Self Destruct Mode', *Journal of Medical Ethics* 32: 125–6.
- HUGHES, B. and PATERSON, K. (1997) 'The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment', *Disability & Society* 12: 325–40.
- JOHNSTON, J. and ELLIOTT, C. (2002) 'Healthy Limb Amputation: Ethical and Legal Issues', *Clinical Medicine* 2: 431–5.
- JORDAN, J. (2004) 'The Rhetorical Limits of the Plastic Body', *Quarterly Journal of Speech* 90: 327–58.
- MACKENZIE, R. (2006) 'Addiction in Public Health and Criminal Justice System Governance: Neuroscience, Enhancement and Happiness Research', *Genomics, Society and Policy* 2: 92–109.
- MACKENZIE, R. and COX, S. (2007) 'Transableism, Autonomy. Self Demand Amputation and Harm: the Doctor's Dilemma', Paper delivered at Interrogating Embodiment, a conference at Keele University, December 2005. *Medical Law Review* forthcoming.
- Manchester Evening News (2005) 'Scandal of the Cancer Fakers' *Manchester Evening News* 21 April: http://www.manchestersonline.co.uk/men/news/health/s/155/155636_scandal_of_the_cancer_fakers.html.
- MAYOU, R. and FARMER, A. (2002) 'Functional Somatic Symptoms and Syndromes', *British Medical Journal* 325: 265–68.
- MEEKOSHA, H. (2004) 'Drifting Down the Gulf Stream: Navigating the Cultures of Disability Studies', *Disability & Society* 19: 721–33.
- O'NEILL, O. (2002a) 'Public Health or Clinical Ethics: Thinking Beyond Borders', *Ethics & International Affairs* 16: 35–45.
- O'NEILL, O. (2002b) *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press.
- RAVILOUS, K. (2005) 'How the Brain Builds Its Image of the Body', *Guardian*, 29 November.
- SALMON, P. and PETERS, S. (2002) 'Doctors and Social Epidemics: the Problem of Persistent Unexplained Physical Symptoms, Including Chronic Fatigue', *British Journal of General Practice* 32: 355.
- SHARPE, M. (2002) 'Unexplained Symptoms and Syndromes', *Clinical Medicine* 2: 501–4.
- SILVERS, A. (1998) 'A Fatal Attraction to Normalising: Treating Disabilities as Deviations From "Species-typical" Functioning' in Eric Parens (ed.) *Enhancing Human Capacities: Conceptual Complexities and Ethical Implications*. Washington DC: Georgetown University Press, pp. 95–123.
- SILVERS, A. (2003) 'On the Possibility and Desirability of Constructing a Neutral Conception of Disability', *Theoretical Medicine* 24: 471–87.
- SMITH, G. (2001) 'Reflections on the Limits of Epidemiology', *Journal of Clinical Epidemiology* 54: 325–31.
- STIRRAT, G. and GILL, R. (2005) 'Autonomy on Medical Ethics After O'Neill', *Journal of Medical Ethics* 31: 127–30.
- TEMPLETON, S. (2006) 'Drug May Heal Livers of Chronic Alcoholics', *Sunday Times*, 24 September: <http://www.timesonline.co.uk/newspaper/0,,176-2372358,00.html>.