

Measuring Health: the disability critique *revisited*

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1. The Global Burden of Disease study (GBD) – from its origins in 1992 and continuing with important methodological improvements today¹ – and in particular the programme of measuring population health by means of DALYs, has been the subject of a substantial critical literature. Recently Colin Mathers has divided these critiques into objections to the quality, or existence, of data used in the calculations, and controversies about the conceptualization of the underlying notions of health and disability.² Objections of the first sort are of great importance,³ especially in light of the objection that GBD results have disproportionately adverse consequences for low and middle income countries as they struggle with allocative decisions,⁴ countries where gaps in valid population health data are the most prominent.

But my focus is with objections of the second sort, and in particular with the **disability critique** of the GBD programme, a critique to which I have myself contributed.⁵ I want to revisit this critique, in light of its recent re-emergence, and suggest that it may trade on a confusion (which I will argue the GBD developers are in part responsible for). My focus is on the putative moral and political concerns with summary measures of population health (SMPH), such as QALYs, DALYs, DALEs, HALEs, rather than normative issues regarding resource allocative applications of these measures – or, in a now somewhat quaintly worded distinction, my interest is in issues of goodness rather than fairness. To be sure, the problems of detaching the two cannot always be avoided, which, indeed is one aspect of the disability critique.

The disability critique is grounded on a suspicion that any approach or mechanism for measuring health is intrinsically prejudicial to persons with disabilities as long as, and to the degree to which, disability is analysed as a decrement in health (or as a 'health problem' or a 'functional difficulty').⁶ I want to argue that this concern about measuring health is fundamentally misconceived, and that while the disability critique does draw out attention to important social injustices involving persons with disabilities, these issues are not conceptually linking to measuring health or SMPH at all. Indeed, my suspicion is that focusing on health measurement is not only misconceived, it may also be counterproductive to the disability rights movement.

The prejudicial impact of measuring health is thought to takes two forms: a) a devaluation of the lives of persons with disabilities (henceforth the **dignity objection**); and b) a downgrading of the value of the potential *ex ante* health outcomes of persons with disabilities (the **justice objection**). The second of these clearly shades insensibly

into objections to health research allocation and various forms of cost-benefit analyses for allocation – the collection of concerns I wanted to side-step. In so far as it is possible to do so, however, I want to consider the justice objection to measuring health in isolation from any potential policy application, including especially health resource allocation.

Roughly, the harm of indignity is social stigma, devaluation and marginalization (with or without psychological impacts such as lowered self-esteem); and roughly, the harm of injustice is an invidious partitioning of humanity by means of an asymmetric valuation of general worth (which may or may not, play out in social policies such as resource allocation). Standardly in the disability critique, both harms are clumped together as ‘discrimination’, but for a variety of reasons I believe this is a misuse of that term and will not follow this practice here.

Both prongs of the disability critique gain purchase on the GBD agenda for three reasons. First because of persistent unclarity about what ‘disability’ means in the programme, or more dramatically, what the ‘d’ in DALYs refers to. Specifically, the disability critique insists that the GBD developers assumed that disability is (or is entirely) a matter of health decrements or problems. And this is not far off the mark. Consider this definition from a recent GBD developmental discussion: “the term disability is used here broadly to refer to departures from optimal health in any of the important domains of health, including mobility, self-care, participation in usual activities, pain and discomfort, anxiety and depression, and cognition and social participation.”⁷ The clear implication here – likely unintended – is that all aspects of human life, including social participation, are determined by ‘departures from optimal health’. The most recent manifestation of the GBD programme⁸ has gone a long way of avoiding this problem, a point I want to return to later.

The second reason is that the GBD programme, from its inception, was not advertised to be a socially and politically neutral, scientific endeavour but rather one that directly serves the interests of health resource allocation in general, and cost-effectiveness analysis in particular. This has made it a simple matter to insist that measurement is in the service of allocation, or that levels of health ‘goodness’ are to be used as scientific justification for levels of allocative ‘fairness’.

Lastly, the GBD programme has been itself burdened with the WHO’s absurdly overbroad definition of ‘health’.⁹ If health is conceived as a hugely important human good, indeed as a state of complete well-being in physical, psychological, social, political and economic dimensions, then it is understandable that someone might object to being labelled ‘unhealthy’. Measuring health in this inflated sense would strike anyone as measuring the state of overall human worth. Fortunately, very few researchers take the WHO definition seriously, or suggest it suitable for measurement purposes. Health can be acknowledged to be the intrinsic and instrumental human good it obviously is without it being the human good. If nothing else, the WHO definition, and expansive definitions like it, conflates the intrinsic state of health of a person with the determinants (social or biological) of that state and, more importantly, the

consequences of that state. Bundling everything positive in a person's life that might flow from good health into the concept of health is just asking for conceptual trouble. A far more sensible, working conception of health is one in which health is an intrinsic human good (by virtue of being a component of human well-being) and an instrument good (as it contributes to the production and maintenance of other components of well-being) but is comprised entirely of states of functioning of the human body (and mind if one is a dualist). Health problems, therefore, are functional decrements in some domain of functioning, as determined by biostatistical normality or some other plausible and operational threshold norm.¹⁰ This is my working sense of 'health' for the discussion that follows.

2. Although there are many versions of the disability critique, two propositions (the second a modified version of the first) lie at its core and together lend support to the dignity and the justice concerns:

A) *disability does not involve any health decrement at all*, so measuring health is at best irrelevant to, and at worse, prejudicial for persons with disabilities; and

B) there is a *health decrement component of disability, but it is relatively inconsequential* as compared to the disadvantages that result from physical, social and attitudinal environmental barriers.

Support for the first claim is provided by one of the following additional assertions:

- 1) A disability – being unable to see, for example – is not a *health problem* at all (i.e. functional decrement is not a health decrement).
- 2) Being unable to see is not a *problem* at all (i.e. the disadvantages such as they are socially created, or uncompensated when they could very well be were society differently organized).¹¹
- 3) A health problem is an acute problem, not a chronic condition, so incidences of blindness (even if they start out as health problems) are no longer health problems since the blind person cannot be cured and does not require medical interventions for 'treatment' of blindness.

In whatever form, these claims – coupled with inflated conceptions of health such as WHO's – lead naturally to the complaint that being labelled 'unhealthy' is an affront to dignity, a kind of insult. But as frequently occurs with the disability critique what may initially strike one as a peculiar complaint, on closer inspection reflects a genuine concern. People with disabilities argue to be viewed as unhealthy means that one is thought to have specifiable health requirements, and so the need for health services. But, in practice, these services are provided by social arrangements that are demeaning irrespective of legal and social protections of autonomy and confidentiality. The problem lies with the professional classes of 'experts' who purport to have a fuller and clearer

understanding of the body and mind of the 'patient' than she has of herself. Hence, being labelled unhealthy implies that one must remain, potentially indefinitely, under the auspices of what for many people is an undignified, if not unjust, social and professional regime.

Put this way, the complaint resolves into to what, in the WHO Health Report 2000 was issues of health system 'responsiveness'.¹² And so framed, I believe the complaint is justified since the evidence is that people with chronic health conditions are regularly treated, whatever the nature of the health system, in an undignified, even insulting manner. It is important to notice, however, that this particular social problem has nothing to do with the conceptualization of health and disability or putative moral problems with measuring health.

If we move to assertion B) – that there is a health component to disability, but it is not determinative of the overall experience of disability – we approach a spectrum of accounts that form the modern consensus about the model or concept of disability. This indeed, is the heart and soul of the disability critique.

At the extreme end of these accounts of disability is what is often called the social model of disability, an account that insists that the manifold and manifest disadvantages of being a person with a disability have nothing much to do with any intrinsic feature of a person, but rather with what might be called the social reception of perceived abnormalities in mind and body. Adherents of the social model do not deny that people have health problems that require health interventions, although they admit this with consider reluctance in order to distance themselves from what the 'medical model of disability'. Hence, Michael Oliver has notoriously stated that, '[d]isability has nothing to do with health'.¹³ What it has to do with is stigma, prejudice, devaluation, discrimination and a host of interrelated social responses to 'difference' that support and apparently justify undignified and unjust social practices. Disability is socially-created disadvantage.

The social model was born out of, and became a highly successful advocacy tool for political movements during the 1970's and 80's that resulted in some essential improvements in the lives of persons with disabilities.¹⁴ The recently enacted United Nations *Convention for the Rights and Freedoms of Persons with Disabilities*,¹⁵ can be directly linked to social movements, at least in the high income countries, that chanted the social model slogan. In light of its obvious political success, it is somewhat churlish to criticise the social model, but is now apparent that it was never intended as anything more than a political slogan. Taken literally, it implies that people with disabilities have no health resource requirements by virtue of their disabilities – a proposition that many ministers of health would be pleased to hear, but which, to my mind, easily qualifies as both unjust and undignified.

The pure social model is slowly fading from the landscape because of a far more plausible framework for analyzing disability now in place. It goes by various names and has arisen in several disciplines, health and social scientific,¹⁶ but the version I outline

here is by far the most highly developed and scientifically grounded model in this tradition. It is the model found in the WHO's *International Classification of Functioning, Disability and Health (ICF)*.¹⁷

3. It has long been recognized by non-medical health professionals who deal with functional problems that the term 'disability' is used ambiguously to refer to a lived experience of functional limitation, on the one hand, and the causes of that experience on the other. In part to avoid confusion, for decades, physical and occupational therapists distinguished between underlying functional problems, or impairments and, the myriad ways that impairments play themselves out in a person's life and social roles – the disability. Impairments are health issues, whether acute or chronic, whether temporary or permanent, and whether they require health interventions or not. They are health issues because they refer to functions of the human body or mind, and so are intrinsic, or 'under the skin' attributes of people as biological entities.

That being said, it is equally obvious that how impairments play out in a person's life depends, sometimes to a large extent, on features of the person's physical, human-built, social, economic and even political environment. Two people with identical impairment profiles may live vastly different lives because of the environmental conditions in which they live (wheelchair use in Manitoba in the winter is a different proposition than in Malibu in the summer), the requirements and expectations of their jobs, their family responsibilities, their economic status, the availability of accommodations and the level of accessibility. Because of this, neither impairments nor the underlying disease, disorder or injury ('health condition' for short) are reliable predictors of disability. Environmental factors make a difference.

Disability is there an outcome of interactions between intrinsic, health features of the person (the person's health states), and extrinsic features of the person's overall physical, human-built, social and attitudinal environment (the person's context). This is the conceptual basis for the ICF. The ICF models this complex relationship by distinguishing the health components of disability – impairments and limitations of capacity to carry out actions, or Activity Limitations – and the outcomes the interaction between these health states and Environmental Factors, which are called Participation Restrictions. Activities and participation domains range from the extremely simple movements and behaviours, to simple and complex activities of daily live and, at the other end, social roles and complex social behaviours. The point is to capture everything that human do or become.

The decision was made during the revision process that lead up to the current ICF – and in retrospect was a mistake – to use the term 'disability' as a label for all three dimensions – impairments, Activity Limitations and Participation Restrictions – singly or in conjunction. I will continue to do so, with occasional asides to keep the elements straight.

The salient feature of the ICF model for this discussion is this: disability is a health issue, but not entirely a health issue, since the dimension of participation is jointly

determined by health states (impairments and capacity limitations) and the overall configuration of a person's environment. ICF itself is a classification tool, a language designed to collect and codify information at all levels, including information about environmental factors. No assumption is made about the relative causal impact of impairments or environmental factors on various participation outcomes. ICF provides the model and language in terms of which researchers can make this determination in particular cases.

To change idioms somewhat, the ICF model is compatible with (although it doesn't explicitly mention) social as well as biological determinants of health conditions (once again, the shorthand term for diseases, disorders, trauma and natural phenomena like ageing). Its focus, however, is on social as well as health determinants of disability. The lived experience of disability is explained by health and environmental variables.

More important for our discussion is the operational difference between the health component and the participation dimension. It comes to this: The health component of disability is a matter of a person's inherent or intrinsic, under the skin 'capacity' – what this body (and mind if you are dualist) can do. The lived experience of disability is a matter of how the person actual 'performs' in his or her actual world.

My claim is that a persistent muddling of this distinction between **health capacity** and **overall performance** is responsible for much of the disability critique. Although conceptually clear, the distinction is susceptible to conflation for three reasons:

First, the English word 'capacity' is not the best choice since it is ambiguous in just the wrong way. If I have lost a leg by amputation I 'cannot' walk; but if I can a suitable prosthetic, I 'can' walk. True, but only because the sense of the word 'can' has changed. Providing me with a prosthetic has no effect whatsoever on my inherent health state of missing a leg. In other words, the prosthetic has no effect on my capacity to walk. What has changed is not my capacity, but my performance – what I actually do. Because the English 'can' flips back and forth between the 'can' of 'capacity' and the 'can' of actualized capacity, we consistently trip over the word in this context.

Secondly, the distinction between what is intrinsic to the person and what is part of the environment is conceptual. Yet in practice, there are borderline cases. A surgically implanted pacemaker is, despite its location and function, a part of the environment, not part of the person. Most medication, by contrast, although at some point a part of the external environment, alters the physiological functioning of inherent processes: the angiotensin-converting-enzyme inhibitor I am now pleased to take daily changes me (i.e. my functional capacity) by normalizing blood pressure by means of vasodilatation.

Finally, the distinction has nothing to do with how we label the 'intervention', or how we name the professions of the people who provide the intervention. Provision of reading glasses may be a service funded by health insurance and prescribed by a health professional, but what glasses do is not a health change; glasses change my reading performance, not my reading capacity (we would need laser surgery for that).

4. To recall, the second argument that forms the disability critique of measuring health for social purposes is that the health component of disability is relatively inconsequential as compared to the disadvantage that result from environmental barriers. The ICF approach to disability neither confirms nor disconfirms this claim, it rather offers an explanatory matrix for describing and testing claims about the source of participation restrictions. If we are conscious of the capacity/performance distinction, what can we make of this aspect of the disability critique? Consider these examples:

1) The direct impact of depression on a person's level and efficacy of participation in most life areas is far greater than the impact of the person's environment. Put differently, very little can be accomplished by altering a person's environment in order to increase participation. Some modest improvement might result when co-workers are educated in the manifestation of depression, or the employment situation is flexible enough to accommodate unpredictable absences or performance reductions. But generally, the greatest impact on the participation of persons with depression comes about from successful medication, that is, a health intervention.

2) Research on various forms of facial disfiguration, scarification or pigmentation such as vitiligo has suggested that the participation impact of these impairments is almost wholly the result of social response – avoidance, stigmatization, and discrimination in employment, social relationships and other social interactions.¹⁸ The health component in these cases has an almost negligible direct impact on participation. So in this case, the only relevant intervention would be some form of environmental alteration.

The disability critique works well with facial disfiguration, but not very well with depression. More generally, the relative impact of functioning-altering interventions (typically health interventions) as opposed to environmental interventions (building redesign, curb cuts, employee education, and so on) can not be answered a priori: we need to do the research to find out. The salient policy question for disability is therefore: in order to increase the participation of persons with disabilities in society, is it more cost effective to provide health or rehabilitation interventions or to spend that money making the environment more accommodating and accessible in order to increase the participation?

But again, even when the disability critique is correct and we should change the environment not the person, it is correct because it focuses on participation outcomes, not capacity levels. So, to focus the critique on measuring health is simply misplaced. That's not the problem.

5. But, it might be objected, is the disability critique plausible even in the most favourable case of facial disfiguration? Although adverse social reaction to the facial disfigurement is intolerant and cruel, still people are reacting to something (that is, the

disfigurement in some sense 'causes' the reaction); isn't the root of the problem a capacity limitation, namely the disfigurement?

This is going too far. The easiest way to see why this is unfair to the disability critique is to look at potential resource allocation implications of this response. Consider this analogy. Suppose as a society our primary aim is to maximise a sense of self worth among our citizens by means of the distribution of resources and opportunities. Since ours is, as a matter of troubling fact, a racist society, our scientists have developed a valid and reliable measurement instrument for self worth and have used it to verify the obvious, that blacks in our society have, in general, a lower self-worth than whites. Should we be convinced that self worth-enhancing resource distribution to blacks is inefficient since the outcomes in self worth are not as great for them as would be yielded by the same resources for white people. Would not blacks be morally justified in insisting that measuring self worth is invidious as it perpetuates the indignity of racism and the potential for unjust distribution?

If blacks insist that more and more efficient ways of measuring self-worth, without addressing the underlying racism, is potentially harmful to them, how should we respond? Surely it would be hollow, disingenuous or just naïve to respond that refining the science of measuring self-worth is a politically-neutral scientific activity that itself causes no harm. Nor could we dismiss the claim as factually false on the grounds that, whether they like it or not, blacks have a demonstrably lower sense of self worth. True, blacks might indeed deny this fact for political-strategic reasons, but denying it is not at the heart of their objection.

It seems to me that it would be both strategically prudent, and more defensible, for blacks to broadcast the fact that they are a sub-population with lower sense of self worth since it is evidence of the social injustice they are objecting to. A self worth measurement tool is politically valuable as it demonstrates that one important impact of racism can be measured as a harm. Is it not better to take the argument against racism out of the domain of speculation and into the domain of scientific measurement? It may indeed be demeaning to admit that, as a black, one has a higher chance of suffering in self worth; but if it is true, then denying it is ultimately futile, while broadcasting the fact might be strategically successful to attacking racist practices.

Of course, both blacks in our hypothetical and disability advocates might want to respond that we are being politically naïve. Whether theoretically useful or not, a concerted scientific programme of measuring self worth or of measuring health is at best irrelevant and at worse diversionary as it fails to address the central issue of undignified and unjust social response to race or impairment. At this point, the debate resolves into a discussion of political tactics, where both the objectives and issues about the efficacy of means to reach those objectives are far more difficult to be clear about.

Still, the underlying conceptual point remains. Assessments of health are normative claims in one moral dimension and objections to resource allocation on the basis of assessment of health are claims in another dimension. The importance of insisting on

this distinction has been made more than once in the development of GBD. John Broome, for example,¹⁹ has objected to what he perceived as the infusion of justice considerations in the 'goodness' exercise of determining disability weights for DALYs by insisting that "... fairness has no place in a measure of health... A measure of health is aimed at measuring the goodness of health, and fairness must be accounted for separately from goodness." And again: "the truth is that, if one patient will live a better life than the other, more good would be done by saving her than by saving the other. We should not hide from this truth." At the same time, Broome has argued, our moral qualms here simply indicated that 'doing the most good' may be a morally repugnant criterion for allocation. Dan Brock has made analogous points in his 'separate spheres' argument.²⁰

Measuring health offers the prospect of a degree of scientific rigour that is (hopefully) transparent, reproducible and not easily be ignored by politicians and health bureaucrats. The measurement strategy, moreover, does not dictate the distribution strategy: That paralysis is a worse health outcome than myopia may suggest a distribution strategy of providing the person with paralysis fewer health resources. But if we are impressed by a rule of rescue or Parfitian prioritarianism²¹, we might argue that priority be given to the worst off. The goodness of a health outcome does not determine allocative strategies.

6. I have argued that the conceptual distinction between capacity and performance is hugely important in this context, and that, for different reasons, so too is the distinction between measurement and distribution (or goodness and fairness). What the disability critique, especially in its more recent reincarnation, has failed to see, I believe, is that these two conceptual and moral distinctions are strongly related. Let me give one important example of where this has led critics astray.

Daniel Reidpath and colleagues have ably presented a series of objections to DALYs, while remaining sympathetic overall to the GBD project and the importance of measuring health for policy purposes.²² Like many commentators, their focus is on the valuation exercise for determining disability weights, the relative 'burdens' of different health conditions and risk factors, an essential dimension of all summary measures of health. Reidpath and colleagues focus on the line between health and environment (or 'context' as they call it), and what they see as the impossibility valuating the 'burden' of a health condition without taking into account different physical, social and cultural environments (or context for short) that make a difference. Theirs is an objection to the universality of disability weights (the claim that "blindness in the United Kingdom has the same disability weight as blindness in Niger in spite of structural interventions in the UK that make the disability less severe than in Niger."²³)

Reidpath's argument is best summarized by his favourite example:

The average disability weight for paraplegia for instance is 0.671. This average disability weight, however, misrepresents the reality of the life of a rural dwelling Cameroonian with paraplegia compared with an urban dwelling Australian with

the same condition. People with paraplegia in Cameroon lead a highly stigmatized life of almost complete social disengagement; there is no social and environmental infrastructure to support their disability and moving around their environment unassisted is impossible. In contrast, people with paraplegia in Australia experience a much easier life; the support infrastructure is considerably better, and significantly, the provision of infrastructure is mandated and enforced through social systems such as building codes.

In other places, Reidpath and colleagues have argued that this is not a trivial matter since there is a measurable 'development gradient' to severity of burden, so that if one uses the Australian experience as the standard for the burden of paraplegia one will be seriously underestimating the burden of that same condition in Cameroon.²⁴ Conversely, it has been argued that diseases typical of poor populations are assigned by GBD a relative small burden because the values of "wealthy experts" in privileged countries with responsive health care systems have determine the disability weight of those conditions.²⁵

It is hard to blame Reidpath in pursuing this line since in a sense he is simply following a direction that Murray and colleagues themselves – mistakenly I believe – began with Murray's important 1996 paper "Rethinking DALYs."²⁶ Reidpath traces various failed attempts by Murray and colleagues to deal with context – first relying on an earlier WHO distinction between disability and handicap,²⁷ then trying to inject 'average handicap' or 'average social milieu',²⁸ before a short-lived flirtation with the 'veil of ignorance'.²⁹ Murray was persuaded that in order to assess the burden of a health condition, one need to take into account – not merely the adjustments of age and sex³⁰ – but something about the context of the experience of the condition. It was a balancing act between universality and validity. On the one hand Murray realized that, as he put it : "If the burden estimated from a given condition were to be completely context specific, meaningful comparisons across communities or within communities over time would be essentially impossible"³¹ On the other, he appeared to be convinced by the argument that since the object of the valuation exercise was to provide a measure of the burden of disease in populations, as that burden is experienced by real people in actual situations, then some features of the 'actual situation' need to be accounted for. But what features and how much needs to be included? I believe there is simply no non-ad hoc answer to this question, because it is confusing, at one time, both capacity and performance components of disability and the difference between goodness and fairness. Reidpath, who fully realizes what is lost when universality is lost, nonetheless opts of some undetermined level of 'social context' and leaves it at that.

Murray has gone on to put his faith in the 'person trade off' protocol as a procedure for eliciting social values, further validated the exercise by sophisticated multi-method triangulation techniques.³² But there may be a better way to respond to Reidpath's critique. For it is significant that he claims that the problem with DALYs is that they ignore the "social determinants of the severity or impact of the disease" and that "[h]ealth conditions are necessarily an interaction between a person and their social, cultural, and environmental contexts."³³ These are clues that he is conflating health

capacity with overall, fully contextualize, performance. Or more simply, he is confusing a state of health with the experience of the impact of a state of health on one's life. These are different things: the first is a matter of diminished capacity, the other diminished performance.

Consider these examples: *A* gets the flu and uses one of his job's sick days (a day he otherwise would have lost at year's end) in order to watch last year's *Prison Break* on DVD. *B* gets the flu, misses an important meeting and is fired. Do *A* and *B* experience different health conditions? Of course not. The difference in context makes a difference in the impact, of the same health condition. Context makes all the difference to impact.

Other examples can easily be generated, using severe and chronic health conditions. Everyone agrees that the physical, social, cultural, political context may make all the difference on the lived experience of a health condition; the problem is that people interpret that to mean that the health condition is altered by context. But it is not. The lived experience and impact of paraplegia in Cameroon is very, very different from that in Australia; but the health condition of paraplegia is the same the world over.

One needs to quickly add that of course the context *can* change the health condition in a variety of ways, including making it worse or better. High levels of pollen in the air makes asthma worse and physical and social environments can have a profound effect on mental illnesses. But context changes the health condition when it *changes the health condition*, when, that is, it alters the nature and level of incapacity. When it changes the person. How an environmentally worsened health condition plays itself out on people's lives is another question. Depending on the circumstances, a context that worsens the health condition may improve the impact on the person's life, or not. A context that moderates health condition (making it less severe than it might otherwise be) may be a context in which the less severe health condition have a worsened impact on the person's life. Severity of health condition and impact of health condition are different things, complexly related through the context.

Not to belabour the point, but the lived experience of a health condition is the outcome of an interaction between it and the context. That much is trite. But the health condition itself is not the interaction of another health state and the context. That is a confusion between a health incapacity and a performance outcome.

In effect I am arguing that a true burden estimate for a disease or risk factor has to be the burden of the disease or risk factor 'within the skin', a possible way out for Murray that Colin Mathers offered in 1997,³⁴ and which Reidpath quickly dismisses as an attempt at 'health in a vacuum'. To revert to ICF language, the burden of a disease should conceptually be the burden of those impairments and activity limitations that delimit the health component of disability, namely those levels of functional decrement and incapacity that are intrinsic to the person, entirely removed from context.

Another caveat is immediately in order. This is a conceptual point, not a measurement strategy. Whether it is feasible, by means of self-report surveys and questionnaires or

clinical protocols, to actually elicit the health component of a person is another story entirely. Presumably, a medical clinician when diagnosing is making an objective determination of the health state, not how this plays out in her patient's life. But the conceptual line between the two is constantly crossed (and indeed, maybe that is good clinical practice). Perhaps a measurement strategy can be fashioned statistically, and validated in its own terms, that can accurately capture capacity information. That's for others to decide.

The Reidpath critique, I believe, rests on a conflation of capacity and performance, or in disability terms, they believe that what is true about the participation component of disability is also true of the health component. Other commentators have compounded the confusion by mixing in objections to 'the medicalization of disability'. For example, Dan Mont in a recent *Lancet* piece³⁵ linked the Reidpath point to the claim that disability is not a matter of health, producing the following confusing amalgam:

According to DALYs, an individual with a disability necessarily has diminished health compared with a person without a disability. This reasoning is inherent in the old medical model perspective without taking environmental factors into account. But, using the social model of disability, which focuses on quality of life, disability as so-called negative health is a flawed formulation. People's well-being is just as much a function of their environment and the supports they possess as it is the physical or mental limitations that a particular medical condition is associated with, independent of those supports. Moreover, as stated earlier, people with the same diagnosis have very different lives for many reasons, and yet DALYs weight their disorder the same (with questionable weights).

If I am correct that the Reidpath critique can be answered by emphasizing the distinction between capacity and performance – the health component of disability and the performance component -- what remains of the disability critique is that it is undignified and unfair to ignore the experience of persons with disabilities in the valuation of health states. But here again, I believe, the disability critique is tilting at windmills.

Taking account of the difference between capacity and performance can also explain why the objection to the underlying 'equality' framework of the GBD was based on a confusion. As Murray put it in 1996, the normative basis of DALYs is based on the proposition that "The burdens calculated for like health outcomes should be the same."³⁶ Murray's point is that it should not make a difference, to the burdensomeness of the health condition, whether it exists in a person in New Jersey or New Delhi. The lived experiences of these two people will be very different, their rates of participation may be different, but their health condition is the same, and should be valued the same. When Reidpath³⁷ and others object that Murray is making the simple error of confusing equitable treatment with the same treatment, he is ignore the manifest differences in circumstances that dictate, for the sake of equality, differences in treatment. But these differences are a matter of how the health conditions plays itself out in a person's life, they are not differences in the nature of the health condition itself. One treats the same

health condition in two people the same, because with respect to the burden of the health condition they are 'similarly situated'.

7. The debate over who should take part in the disability weighting or valuation exercise may seem to the causal observer as an argument of who is more biased, health care professional experts or persons with disabilities. But in fact the debate raises interesting moral-epistemological issues about what Amartya Sen has called 'positional objectivity':³⁸ Should we uncritically accept the self-report valuation of a condition of life (be it a health condition or a social condition) when we have good reasons to think that the individual is merely reflecting the culture's devaluation of people like him or her?

One interesting variant of this debate concerns phenomena of **adaptation**, in which an individual is perforce required to alter life plans, expectations or lifestyles in light of dramatically change circumstances, such as are brought on by the onset of a debilitating disease or an injury. The problem with adaptation (or coping, adjustment, or acceptance) flows from empirical findings suggesting that people in a given health state tend to rate that state more favourably than those people asked to rate it hypothetically, and adaptation is claimed to be the cause of this difference.³⁹

Although there are serious measurement problems caused by potential shifting in valuation over time and place, the ethical concern is whether it is ever fair to accept this form of favourable bias. De Toqueville's 'happy slave' is still oppressed, and Amartya Sen's resident of the Indian state of Bihar, who has no realistic access to health care, may be resignedly content with extremely poor levels of health.⁴⁰ These and other examples are taken to be counterexamples to utilitarian distributive schemes that depend on self-reported utility measures, but they also point to a deeper irony about the disability critique: the demand to respect the health state valuations of those in those states would appear in practice to direct resources away from those with severe health problems – since adaptation is more likely for them – to those who experience far less severe problems – for which adaptation is less likely.

The moral landscape of adaptation may, in fact, be considerably more nuanced than this, as Paul Menzel and colleagues have argued.⁴¹ Menzel et al. disaggregate the adaptation phenomena into several components, some of which support our moral qualms about using patient's assessments of health states, and others that do not. On one side are components of adaptation that constitute 'laudable effort': skill enhancement, activity adjustment, and substantive goal adjustment. These are adaptation phenomena in which people are, admirably, 'making do' and which, prima facie, support our intuitions not to use post-adaptation valuations for resource allocation on fairness grounds, since efforts – rather than their valuations – argue for skewing resource allocation in their favour, as compensation for great effort.⁴² The moral dilemma, then, is whether we should ignore laudable effort adaptations, or reward them.

By contrast, some adaptation phenomena cognitively distort one's perception of what good health is like -- leading one either to refuse to recognize that one's health is poor,

or to suppress one's knowledge of the functional advantages of better health. Menzel and colleagues argue persuasively that since these are cognitive distortions we have good reason to ignore them for valuation. And they are undoubtedly right about that.

Menzel and colleague then turn their attention to the happy slave problem, Sen's entrenched deprivation objection, and, finally to our general intuition that, however laudable adaptation may be, it is still regrettable and unfortunate. They cautiously conclude that only the cognitive distortions absolutely disqualify patient judgments. The other adaptation phenomena are less clear, morally, either because, whatever the cause of the adaptation, the resulting valuation is still meaningful, or because there is no reason to think that non-patients, suitably apprised of the complexities of adaptation, could not fairly take these phenomena into account.

But, in a sense all of this misses the point. We should not conflate the issue of the validity of self-report valuation and the fairness of using self-report valuation for resource allocation. The primary moral concern of adaptation is with the latter question - this is certainly what Sen, Ronald Dworkin and other critics of 'welfarism' in distributive justice have in mind.⁴³ If our concern is with unfairness, then we have moved beyond a concern about the valuation of health conditions to the 'burden' of the lived experience of disability, which is determined not merely by the health condition, but by the context in which people in that condition have to live. And here the adaptation issue takes on additional, and not often appreciated dimension, namely that the need to enhance one's skill set, adjust life goals, lower one's expectations and increase stoicism, all of this can be necessitated as much by an hostile social environment as by the incapacities brought about by a health condition. Here the disability critique comes back on line, although, once again, it has little to do with measuring or valuing health states.

But validity of health valuation is a different matter again. Here the worry about the effect of adaptation is misplaced because it is far more relevant to **evaluation** than valuation -- that is, to the subjective appraisal of the lived experience of a health condition rather than to ranking the 'burden' of health conditions. We have lots of evidence of wide variations in levels of eudemonistic subjective states such as satisfaction or happiness associated with the same health condition -- the work of Daniel Kahneman among others makes it clear that self-reports of subjective utility states are influenced by a wide variety of contextual phenomena.⁴⁴ But it is simply not clear that a person with paraplegia would not, however well adapted she or he was, rank paraplegia as a more serious health condition than vitiligo. Valuation of health conditions may not be affected by adaptation phenomena. It is not clear how much 'bias' adaptation would actually cause for valuation, nor, in the end, whether people with disabilities would ranking health conditions differently than professional experts.

8. The 2008 final draft, 'Operations Manual' for the Harvard Initiative for Global Health⁴⁵ makes substantial changes to the part of the GBD programme that was responsible for much of the disability critique, namely the determination of disability weights. As the Manual now puts it: "The GBD Study conceptualizes "loss of health" as decrements in capacity in health domains." The performance/capacity distinction is

raised, and the point is made that – as argued above – that changes in a person's environment, though they may have a profound difference in their levels of actual participation, will not normally have any effect on capacity, that is, the health of the individual:

“To the extent that performance reflects environmental barriers, which can vary with time, social or physical setting, and as individual circumstances change, it is probably not congruent with most notions of health. Thus, if a person cannot climb flights of stairs in his/her usual environment because the stairs are too steep, most people would not say that the person's health state had changed if the stairs were modified to be less steep. This is consistent with the notion of health as an attribute of individuals rather than environments (though environmental factors may be causal for health states).”

Health states, in short, are neither general well-being nor participating in society, although they affect these aspects of life and are affected by them. Gone is the ill-fated attempt to include some features of a person's context for valuation (e.g. 'average social milieu'); now the valuation is strictly a matter of valuing the severity (in terms of professionally-selected sequelae) of the disease, disorder or injury. Disability weights remain cardinal measures on a scale ranging from 0 (ideal health) to 1 (death), but now they will clearly be measures of health decrements (or as I prefer to say, the health component of disability). Gone too is the attempt to measure the 'utility' associated with health states, or the contribution of health to overall welfare. Rather than using an interactive 'person trade off' protocol to capture social preferences, valuers will now be asked a series of discrete choice questions to indicate which of a pair of health states they would regard as a *worse* state of health. Other changes to the valuation exercise attempt to respond to the complaint that an 'expert panel' is relied on rather than people with disabilities themselves, or at least, 'members of the general community'. Finally, a multi-method approach that has in the past shown that there is more consistency, across valuation approaches, in how health states are ranked than one might have expected is added on.

The obvious question to ask is whether these long overdue methodological modifications will defuse versions of what I have been calling the 'disability critique'. Surely, even people with paraplegia will agree that paraplegia is worse than vitiligo. Presumably, though, those disability critics who have refused to accept any health component to disability will be unmoved by the methodological changes to GBD 2008. And undoubtedly many critics will continue to ignore the difference between capacity and performance – between, that is, the health component and the participation component of disability – and insist that these modifications make no difference.

More sophisticated critics may question whether it is feasible (or psychologically possible) in a valuation protocol to separate the health component from contextual factors, especially when the health states are fairly close in severity: Would not the choice question "Is blindness worse than deafness?" provoke someone to wonder whether it might make a difference where one lives, what one's job is like, what social

services are available, and so on? However attractive this sort of objection may seem, though, it does not get at the underlying conceptual distinction, but rather signals practical or methodological concerns (which can be answered by ever more sophisticated methodology responses).

In the end, my hope is that critics see that their objections to measuring health are misplaced. It should not be either surprising nor particularly worrisome that some states of health are worse than others. Nor is it a question of indignity or injustice to admit that one's health would be better if one was not diabetic, paraplegic or in constant lower back pain. Indeed, however distant this may be from our ordinary conception of 'health', the same should be true about being blind, developmentally disabled or an amputee (examples of what disability critics have long insisted are states that have nothing to do with health). Measuring health is an essential first step to assessing health and health-related needs, which in turn is required to make out the political case for inequitable distribution of health and health-related resources. The disability critic, I suggest, could benefit greatly from a consensus on a valid methodology for measuring health and valuating health states. It would be an important step toward marshalling moral and political objections to the real issue that people with disabilities have historically faced: benign neglect, lack of accommodations, and access to much-needed resources. Rather than disputing the health component of disability, the disability critique should be directed at the inequities in levels and kinds of participation in all areas of social life that has all too often been the fate of persons with disabilities. That is where the moral and political battlelines ought to be drawn.

¹ Murray, C.J.L., 1994. Quantifying the burden of disease: the technical basis for disability-adjusted life years. *Bulletin of World Health Organization* 72, 429-445; Murray, C. J. L., A. D. Lopez, and D. T. Jamison. 1994. "The Global Burden of Disease in 1990: Summary Results, Sensitivity Analyses, and Future Directions." *Bulletin of the World Health Organization* 72 (3): 495–508; Murray CJL, Lopez AD. 1996. *The Global Burden of Disease: A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020*. Global Burden of Disease and Injury Series, Vol. Annu. Rev. Public. Health. 2002.23:115-134; Murray, C. J. L., and A. D. Lopez., eds. 1996d. *The Global Burden of Disease*, vol. 1. Cambridge, MA:Harvard University Press; Murray, C.J.L. 1996. "Rethinking DALYs" In Murray, C. and A. Lopez (eds.) 1996. *The Global Burden of Disease: A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020*. Cambridge, MA: Harvard University Press, 1-98; Murray, C. and A. Lopez (eds.) 1996. *The Global Burden of Disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020*. Cambridge, MA: Harvard University Press; Murray CJL, Acharya AK. 1997. Understanding DALYs. *Journal of Health Economics* 16: 703–30; Lopez, A. D., and C. J. L. Murray. 1998. "The Global Burden of Disease, 1990–2020." *Nature Medicine* 4 (11): 1241–43; World Health Organization. 2000. *The World Health Report, 2000*. Geneva, Switzerland: World Health Organization; Murray, C. J. L., J. A. Salomon, C. D. Mathers, and A. D. Lopez. 2002. *Summary Measures of Population Health: Concepts, Ethics, Measurement, and Applications*. Geneva:World Health Organization; Christopher J.L. Murray, in Murray C.J.L. and Evans, D.A. Health Systems Performance Assessment: debates, Methods and empiricism (Geneva, WHO, 2003);Ezzati, M., A. D. Lopez, A.

Rodgers, and C. J. L. Murray. 2004. *Comparative Quantification of Health Risks: The Global and Regional Burden of Disease Attributable to Selected Major Risk Factors*. Geneva: World Health Organization; Alan D. Lopez, Colin D. Mathers, Majid Ezzati, Dean T. Jamison, Christopher J. L. Murray (eds.) *Global Burden of Disease and Risk Factors* (Washington, Oxford University Press and The World Bank, 2006); Harvard Initiative for Global Health, *The Global Burden of disease, Injuries, and Risk Factors Study – Operations Manual, Final Draft* (31.1.08).

² Mathers, Colin “Epidemiology and World Health” in Holland, W.W., Olsen, J. and du V. Florey, C (eds) *The Development of Modern Epidemiology: Personal Reports from those who were there*, New York, Oxford University Press, 2007 41-60, 56.

³ See for example, Philip Musgrove, Philip “health systems: reflections on WHO’s methods” *Lancet* 2003; 361: 1817–20 and Vicente Navarro, Vicente “ Assessment of the World Health Report 2000” *Lancet* 2000; 356: 1598–601.

⁴ See Almeida, C. et al. Methodological concerns and recommendations on policy consequences of the World Health Report 2000. *Lancet* 2001; 357: 1692–97 and Fox-Rushby, J., “Disability Adjusted Life Years (DALYs) for Decision-Making? An overview of the literature,” 2002 Office of Health Economics, London (and references therein). See also Bobadilla JL. Searching for Essential Health Services in Low- and Middle-Income Countries. Policy Background Study, Report No. Soc-106. Washington DC: Inter-American Development Bank; June 1998 and Gwatkin DR, Guillot M, Heuveline P. The burden of disease among the global poor. *Lancet* 1999; 354: 586–89.

⁵ Bickenbach, Jerome E. “Disability, Justice and Health Systems Performance Assessment” in R. Rhodes, M. Batten, and A. Silvers (eds.) *Health Care and Social Justice* Oxford University Press, 2002 ; Bickenbach, Jerome E. “ Disability and health systems assessment “ in Wasserman, D., Bickenbach, J.E., and Wachbroit, R. (eds.) *Quality of Life and Human Difference* Cambridge University Press, 2005

⁶ I have in what follows tried to balance the concern of bibliographical over-kill with the need for an adequate coverage of what I take to be incidence of, or discussions about, the ‘disability critique of SMPH’ (arranged chronologically): Harris J. 1987. QALYfying the value of life. *J. Med. Ethics* 13(3):117–23; Olsen, J. A. (1993). On what basis should health be discounted? *Journal of Health Economics*, 12, 39±53.; Chamie M. What does morbidity have to do with disability? *Disabil Rehabil* 1995; 7: 323–37; Brock DM. Justice and the ADA: does prioritizing and rationing health care discriminate against the disabled? *Soc Theory Pol* 1995; 12: 159–84; Anand, S. and K. Hanson, “Disability-adjusted life years: a critical review,” *Journal of Health Economics* 16 (1997) 685-702; Hughes, B. and K. Paterson, “The Social Model of Disability and the Disappearing Body: towards a sociology of impairment,” *Disability and Society* 12(3):325-340, June (1997); Olsen, J. A. (1997). Theories of justice and their implications for priority setting in health care. *Journal of Health Economics*, 16, 625±639; Shakespeare, T. (1998). Choices and rights: eugenics, genetics, and disability equality. *Disability & Society*, 13(5), 665±681; Pfeiffer, D. (1998). The ICIDH and the need for its revision. *Disability and Society*, 13(4), 503-523; Brock D. 1998. Ethical issues in the development of summary measures of population health status. See Ref. 15, pp. 73–91; Brock, Dan W. “Ethical Issues in the Development of Summary Measures of Population Health Status” in Field, Marilyn J. and Marthe R. Gold (eds.) *Summarizing Population Health*, Institute of Medicine 1998; AbouZahr C. 1999. Disability adjusted life years (DALYs) and reproductive health: a critical analysis. *Reproductive Health Matters* 7: 118–29; Williams, A. 1999. “Calculating the Global Burden of Disease: Time for a Strategic Appraisal?” *Health Economics* 8 (1): 1–8; Arneson, T. and E. Nord, “The Value of DALY Life: Problems with Ethics and Validity of Disability Adjusted Life Years,” *British Medical Journal* (1999) Vol. 319(7222):1423-5; Nord E, Pinto JL, Richardson J, Menzel P, Ubel P. 1999. Incorporating societal concerns for fairness in numerical valuations of health programmes. *Health Econ.* 8:25–39; Rock M. Discounted lives? Weighing disability when measuring health and ruling on “compassionate” murder. *Social Science and Medicine* 2000;51(3):407–17; Pfeiffer, D The Devils are in the Details: the ICIDH2 and the disability movement *Disability & Society*, Vol. 15, No. 7, 2000, pp. 1079–1082; *Disability World Issue 3* <http://www.disabilityworld.org/> June-July2000/International/DALY.htm; AbouZahr C, Vaughan JP. 2000. Assessing the burden of sexual and reproductive ill-health: questions regarding the

use of disability- adjusted life years. *Bulletin of the World Health Organization* 78: 655–66; Cohen, J., “The Global Burden of Disease Study: a useful projection of future global health?” *Journal of Public Health Medicine* 22:4 (2000) 518-524; Brock, D.M. 2000. Health Care Resource Prioritization and Discrimination Against Persons with Disabilities. in L. Francis and A. Silvers (eds.) *Americans with Disabilities: exploring implications of the law for individuals and institutions*. New York: Routledge, 223-235; Tom Koch “Life quality vs the ‘quality of life’: assumptions underlying prospective quality of life instruments in health care planning” *Social Science & Medicine* 51 (2000) 419-427; Mullahy, J., “Live long, live well: Quantifying the health of Heterogeneous Populations,” *Health Economics* 10 (2001) 429-440; Groce, N., M. Chamie, and A. Me, “Measuring the Quality of Life: Rethinking the World Bank’s Disability Adjusted Life Years,” *Rehabilitation International*, www.rehab-international.org/publications/rivol49/measuringquality.html (2001); Gold, M. R., D. Stevenson, and D. G. Fryback, “HALYs and QALYs and DALYs, Oh My: Similarities and Differences in Summary Measures of Population Health,” *Annual Review of Public Health* 23 (2002) 115-134; Pascale A Allotey, Daniel D Reidpath Objectivity in Priority Setting Tools in Reproductive Health: Context and the DALY Reproductive Health Matters 2002;10(20):38–46; Altman B. Sociology and disability. In Albrecht G, Bury M, eds. *Handbook of disability studies*. New York: Russell Sage, 2002; Allotey P, Reidpath D, Kouame A, Cummins R. The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon. *Soc Sci Med* 2003; 57: 949–58; Reidpath DD, Allotey PA, Kouame A, Cummins RA. Measuring health in a vacuum: examining the disability weight of the DALY. *Health Policy Plan* 2003; 18: 351–56; Allotey, P., D. Reidpath, A.Kouam, and R. Cummins, “The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon” *Social Science & Medicine* 57 (2003) 949–958; [Allotey P, Reidpath D, Kouame A, Cummins R. The DALY, context and the determinants of the severity of disease: and exploratory comparison of paraplegia in Australia and Cameroun. *Social Science and Medicine* 2003;57(5):949–58; Reidpath, D.,P. Allotey, A. Koume, and R. Cummins, “Measuring Health in a Vacuum: Examining the Disability Weight of the DALY,” *Health Policy and Planning* 18(4)351-356, (2003); Nord E. Values for health states in QALYs and DALYs. In: Wasserman D, Bickenbach J, Wachbroit, eds. *Quality of life and human difference: genetic testing, health care and disability*. Cambridge: Cambridge University Press, 2005; Daniel Mont “Measuring health and disability” *Lancet* 2007; 369: 1658–63

⁷ Alan D. Lopez, Colin D. Mathers, Majid Ezzati, Dean T. Jamison, Christopher J. L. Murray (eds.) *Global Burden of Disease and Risk Factors* The World Bank and Oxford University Press, New York 2006

⁸ Harvard Initiative for Global Health, *The Global Burden of disease, Injuries, and Risk Factors Study – Operations Manual, Final Draft* (31.1.08).

⁹ Health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” World Health Organization. *Constitution*. Geneva, World Health Organization, 1948.

¹⁰ See Joshua A. Salomon, Colin D. Mathers, Somnath Chatterji, Ritu Sadana, T. Bedirhan Üstün, Christopher J.L. Murray, “Quantifying Individual Levels of Health: Definitions, Concepts, and Measurement Issues”, in Murray C.J.L. and Evans, D.A. *Health Systems Performance Assessment: debates, Methods and empiricism* (Geneva, WHO, 2003).

¹¹ An example of claim 1 or claim 2 (it is not clear which) is found in the so-call ‘capital d Deaf’ literature, in which deafness is either claimed not to be a health problem or functional difficulty but rather an alternative, and equally valuable, culture (constituted by the language of ASL).

¹² World Health Report, 2000, WHO, Geneva. “*Responsiveness* is not a measure of how the system responds to health needs, which shows up in health outcomes, but of how the system performs relative to non-health aspects, meeting or not meeting a population’s expectations of how it should be treated by providers of prevention, care or non-personal services.” (Ibid., 31)

¹³ Oliver, Michael, *The Politics of Disablement* (London, Macmillan, 1990).

¹⁴ Scotch, Richard K. *From Goodwill to Civil Rights* (Philadelphia, Penn., Temple University Press, 1984).

¹⁵ *Convention on the Rights of Persons with Disability* (United Nations, 2006).

¹⁶ Nagi, Saad Z. *Disability and Rehabilitation: Legal, Clinical and Self-Concepts and Measurement* (Columbus, Ohio State University, 1969); Institute of Medicine *Disability in American* (Washington, Institute of Medicine, Division of Health Promotion and Disease Prevention, National Academy Press, 1991); Amundson, Ron "Disability, Handicap, and the Environment" (1992) 9 *Journal of Social Philosophy*; Bickenbach, Jerome E. *Physical Disability and Social Policy* (Toronto, University of Toronto Press, 1993).

¹⁷ World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva, World Health Organization, 2001.

¹⁸ **Facial scaring literature**

¹⁹ Broome, J. "Measuring the Burden of Disease by Aggregating Well-being" in Murray, C.J.L., Salomon, J., Mathers, C, and Lopez, A. (eds.) *Summary Measures of Populations Health: Concepts, Ethics, Measurement and Applications* (Geneva, WHO, 2002), 91-114 “

²⁰ Dan W. Brock "Separate Spheres and Indirect Benefits" in Murray, C.J.L., Salomon, J., Mathers, C, and Lopez, A. (eds.) *Summary Measures of Populations Health: Concepts, Ethics, Measurement and Applications* (Geneva, WHO, 2002) 115-120.

²¹ Parfit, D. *Reasons and Persons* (New York, Oxford Clarendon Press, 1984) and "Equality or Priority" in Matthew Clayton and Andrew Williams (eds.) *The Ideal of Equality*, (New York: St. Martin's Press, 2000), pp. 81–125.

²² Reidpath, D. Allotey, P., Kouame A, Cummins RA. 2001. Social, cultural and environmental contexts and the measurement of the burden of disease: An exploratory study in the developed and developing world. Melbourne: Key Centre for Women's Health in Society, The University of Melbourne; Allotey, P., D. Reidpath, A.Kouam, and R. Cummins, "The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon" *Social Science & Medicine* 57 (2003) 949–958; Reidpath, D.,P. Allotey, A. Koume, and R. Cummins, "Measuring Health in a Vacuum: Examining the Disability Weight of the DALY," (2003) *Health Policy and Planning* 18(4)351-356.

²³ "Measuring Health in a Vacuum" *Ibid*.

²⁴ Pascale A Allotey, Daniel D Reidpath Objectivity in Priority Setting Tools in Reproductive Health: Context and the DALY *Reproductive Health Matters* 2002;10(20):38–46

²⁵ Trude Arnesen , Lydia Kapiriri Can the value choices in DALYs influence global priority-setting? *Health Policy* 70 (2004) 137–149.

²⁶ "Rethinking DALYs" *supra* n. 1

²⁷ From the predecessor of the ICF, the International Classification of Impairments, Disabilities and Handicaps (ICIDH), 1980; see Murray CJ. 1994. Quantifying the burden of disease: the technical basis for disability-adjusted life years. *Bulletin of the WorldHealth Organization* **72**: 429–45.

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- ²⁸ Murray CJL. 1996. Rethinking DALYs. In: Murray CJL, Lopez AD (eds). *The Global Burden of Disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020*. Cambridge, MA: Harvard School of Public Health; pp. 1–98.
- ²⁹ Murray C, Salomon J, Mathers C. A critical examination of summary measures of population health. GPE discussion paper no 2 1999. Geneva: WHO.
- ³⁰ Brock sensibly noted that these ‘adjustments’ may rely on context rather than health considerations. If the argument for age weighting, for example, was based on the observation that children and the elderly are, generally, economically, socially and psychological dependent on those in their productive middle years, then context has been introduced. Brock, “Separate Spheres and Indirect Benefits.” *Supra* n.17.
- ³¹ Murray CJL, Acharya AK. 1997. Understanding DALYs. *Journal of Health Economics* 16: 703–30, 726.
- ³² Salomon JA, Murray CJL. Estimating health state valuations using a multiple-method protocol. In: Murray CJL, Salomon JA, Mathers C, Lopez AD, editors. *Summary measures of population health*. Geneva: World Health Organisation; 2003, p. 487–98.
- ³³ Pascale A Allotey, Daniel D Reidpath *Objectivity in Priority Setting Tools in Reproductive Health: Context and the DALY Reproductive Health Matters* 2002;10(20):38–46
- ³⁴ Mathers C. 1997. Health expectancies and DALYs: towards consistency of measures. Room Document no. 4, OECD Working Party on Social Policy. Ad Hoc Meeting of Experts in Health Statistics. Paris: OECD; Mathers C, Vos T, Stevenson C. 1999. *The burden of disease and injury in Australia*. Canberra: Australian Institute of Health and Welfare.
- ³⁵ Daniel Mont, *Measuring health and disability*, *Lancet* 2007; 369: 1658–63
- ³⁶ “Rethinking DALYs” *supra* n. 1.
- ³⁷ “Measuring Health in a Vacuum” *supra* n. 22.
- ³⁸ Sen, AK (2002): *Health: Perception versus observation*. *British Medical Journal*, 324: 860–861. Sen, AK (1992): *Positional objectivity*. *Philosophy and Public Affairs*, 22: 126–145. And compare Brock on ‘perspectives problems’ in Brock (1998) *infra* n.6.
- ³⁹ See citations in Salomon, J. and Murraray, C.J.L. “A Conceptual Framework for Understanding Adaptation, Coping and Adjustment in Health State Valuation” in in Murraray, C.J.L., Salomom, J., Mathers, C, and Lopez, A. (eds.) *Summary Measures of Populations Health: Concepts, Ethics, Measurement and Applications* (Geneva, WHO, 2002) 619-626. There is another version of this which I set aside, namely the so-called ‘disability paradox’ in which, evidence suggests, the severer the health condition the more likely that the person experience it will report a higher quality of life. See Albrecht, G.A. and Devlieger, P.J “The disability paradox: high quality of life against all odds” *Social Science & Medicine* 48 (1999) 977-988.
- ⁴⁰ Sen, A. (1992). *Inequality reexamined*. Cambridge, MA Harvard University Press.
- ⁴¹ Paul Menzel, Paul Dolan, Jeff Richardson, and Jan Abel Olsend, “The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis” *Social Science & Medicine* 55 (2002) 2149–2158.
- ⁴² There might also be the argument that these individuals have demonstrated their ability to use resources more efficiently in improving the quality of their lives.

⁴³ Sen A. 1992. *Inequality reexamined*. Cambridge, MA: Harvard University Press and Dworkin, Ronald
"What is Equality? Part 1: Equality of Welfare" (1981) 10 *Philosophy and Public Affairs*, 185-246.

⁴⁴ Kahneman D (1999) Objective happiness. In: Kahneman D, Diener E, Schwarz N (eds) *Well-being: The foundations of hedonic psychology*. Russell Sage Foundation, New York, pp 3–25

⁴⁵ *Supra* n. 1