

**Mistaking the Map for the Territory:  
How Disability Adjusted Life Years Misunderstand Disability  
and Distort Global Healthcare**

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## Introduction

One of the most prominent aspects of contemporary discourse in politics, economics, health care, and development is the focus on data-driven decision-making. Particularly since the fall of the Soviet Union—and, in the international health world in particular, the 1993 World Development Report—policies increasingly must not only do good but also demonstrate cost-effectiveness to be judged successful and worthy of funding. Such an approach has definite benefits—it promises to make our decision making more rational and transparent, and above all to put scarce resources to work in ways that do the most good. However, executing such an approach requires distilling reality, with all its complexity, into single numerical metrics that can be plugged into calculations. This is the reason for the existence of Disability Adjusted Life Years (DALYs)—a single number that aims to capture and quantify the entire spectrum of adverse human health experience, not only that which kills us but that which makes our lives less pleasant, and to compare it to an idealized full healthy lifespan.

The DALY has dramatically altered the way that healthcare decisions are made, shifting the focus of decision makers and shining a light on areas such as mental health that had long gone neglected<sup>1</sup>. However, the use of DALYs is, in Merton's famous formulation, a piece of Purposive Social Action with serious unintended consequences<sup>2</sup>. At their heart, DALYs are built on a presumption—that a life lived with a particular disability is inherently and consistently less worth living than a life without one. In a world where individuals with disabilities are a persecuted global minority, DALYs locate the source of our suffering within our bodies and ignore the societies around us. As a result, the primary decision making metric used to evaluate international health policy rates saving our lives as less worthwhile, and counts the interventions that actually improve them little if at all.

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<sup>1</sup> Farmer, Paul, Jim Yong Kim, Arthur Kleinman, Matthew Basilio. *Reimagining Global Health: An Introduction*. University of California Press, 2013. pp. 226-245

<sup>2</sup> Merton, Robert K. "The Unanticipated Consequences of Purposive Social Action." *American Sociological Review*, Vol. 1, No. 6 (Dec., 1936), pp. 894-904

## The DALY Formula and Loci of Criticism

The academic debate over the use of Disability Adjusted Life Years has been intense since the moment the metric was introduced by Murray in the early 1990s. Some critiques of the DALY are holistic—for instance, the mere existence of the metric has allowed for a far greater use of cost-effectiveness analysis in the health policy realm, and such analysis has had severe consequences, particularly for individuals in the developing world—for instance, DALY-based cost effectiveness analysis undermined effective treatments for MDR-TB in Peru in favor of a DOTS protocol that was viewed as more cost-effective despite very low cure rates—a decision which almost certainly cost lives.<sup>3</sup> (I will return to this cost-effectiveness critique in a disability-specific context.) Gwatkin, Guillot, and Heuveline warned that the use of DALYs would exacerbate the rich-poor health gap because the global aggregation of DALY figures in computing the Global Burden of Disease figures lead to non-communicable diseases, which they argue are the primary cause of disease burden among the well-off, receiving disproportionate attention relative to communicable diseases, which they argued were the primary cause of disease burden among the global poor.<sup>4</sup>

Much of the sharpest initial criticism focused on specific aspects of the DALY formula, which itself is the sum of two distinct calculations: Years of Life Lost, which aims to measure the amount of premature death caused by health conditions, and Years Lost to Disability, which aims to measure the loss of utility experienced by individuals with disabilities, relative to the utility they would have experienced without disabilities. Criticism around three areas in particular actually succeeded in changing the metric in 2010. The initial 1990 formulation of the DALY assumed a biologically-inherent gap in life expectancy of roughly 2.5 years between women and men, something criticized as potentially skewing policy incentives by making DALYs among

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<sup>3</sup> Farmer et al. *Reimagining Global Health*. pp. 236-241

<sup>4</sup> Gwatkin, Guillot, and Heuveline. “The burden of disease among the global poor,” *The Lancet*. Volume 354, Issue 9178, 8/14/99, pp 586-589.

women look greater than among men, which would lead to greater investments in healthcare interventions that target women, leading to a wider gender gap in life expectancy, and so on.<sup>5</sup> Significant ire was also directed at the use of a 3% per year time discount rate—with the result that saving one life today is worth as much as saving five lives in 55 years. This is typical for dollar-value calculations, usually based on the existence of interest rates and preferences for present over future consumption, but given that DALYs are explicitly not a measure of capital, little justification for such a time preference seems to exist.<sup>6</sup> Finally, the initial formulation of DALYS included an age weighting structure, in which the lives of children were initially rated relatively low, then rose with age to a peak around 25 years of age, before consistently falling as individuals grew older. As a result, a year of healthy life at age 70 was worth only 46% as much as a year of life at 25—an additional correction on top of the fact that the death of a 25 year old would already incur 45 more Years Lost to Death than the death of a 70 year old, and that a 70 year old would be proportionately more likely to have a disability.<sup>7</sup> All of these aspects of the formula were not used in the 2010 Global Burden of Disease study and were formally dropped in 2010: years lost to death now use a maximum age of 91 for both men and women, and DALYs now no longer include age weighting or time discounting.<sup>8</sup>

However, while the methods of calculating them have changed, one piece of the DALY that remains despite intense critique is its *raison d'être* as a metric: disability weights. These weights, which allow the metric to claim to quantify morbidity as well as mortality, are numbers ranging between zero and 1 for particular disabilities, where a score of 0 corresponds to having

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<sup>5</sup>Farmer et al. *Reimagining Global Health*. pp. 232; Anand, Sudhir and Kara Hanson “Disability-adjusted life years: a critical review.” *Journal of Healthcare Economics*. 16(6). December 1997, pp. 685-702.

<sup>6</sup> Anand and Hanson.

<sup>7</sup> Farmer et al. *Reimagining Global Health*. pp. 233, Anand and Hanson.

<sup>8</sup>WHO Department of Health Statistics and Information Systems, *WHO methods and data sources for global burden of disease estimates 2000-2011*. November 2013

no disability at all, and a score of 1 to being dead. Some conditions have different weights for mild, moderate, and severe cases, or a binary for treated vs. untreated cases. However, many conditions, including “Conduct Disorder,” Gastric Bleeding, Speech Difficulties, and “Severe Wasting” still have only a single value. At present, the least severe disability on the scale is the long term impact of a treated fracture, at 0.003, while the worst is untreated schizophrenia, with a weight of 0.756. This weight is multiplied by the number of years than an individual has lived with the disability to compute their Years Lost to Disability—in essence, according to the metric, the years worth of utility that they lost, compared to what they would have experienced if they had had no disability at all.<sup>9</sup> Since these weights range linearly from 0 to 1, we can essentially treat them as percentages. For instance, my mild motor impairment, attention deficit disorder, and mild depressive episodes would be judged to make a year of my life worth 1%, 4.5%, and 14.5% less worthwhile than a year of a non-disabled person’s life. Since these conditions are not considered co-morbid under the rules of the metric, we can sum them to get a cumulative disability weight for me of 0.2, and find that over the course of my 27 years of being alive, my years lost to disability are 5.4 . I suppose I should feel fortunate that my life is still judged to be relatively worth living.

The way these weights are calculated has changed over the years, but their basic nature has not changed—specifically, that they are based on opinion, not medical data. From 1990 through 2010, DALY weights were calculated by convening small groups of doctors and other medical experts and having them rank particular disabilities. The first set of rankings were achieved using two Person Trade-Off questions that explicitly asked respondents how much the lives of individuals with particular disabling conditions were worth relative to the lives of non-disabled individuals. First PTO 1, which asked:

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<sup>9</sup> *WHO Methods and data sources*; Salomon, Josua A. et al. “Disability weights for the Global Burden of Disease 2013 study—supplementary appendix” [The Lancet Global Health](#). Volume 3, Issue 11, November 2015,

You are a decision maker who has enough money to buy only one of two mutually exclusive health interventions. If you purchase intervention A, you will extend the life of 1000 healthy [non-disabled] individuals for exactly one year, at which point they will all die. If you do not purchase intervention A, they will all die today. The alternative use of your scarce resources is intervention B, with which you can extend the life of  $n$  individuals with a particular disabling condition for one year. If you do not buy intervention B they will all die today; if you do purchase intervention B, they will die at the end of exactly one year.<sup>10</sup>

1000 would be divided by  $n$ , and the resulting figure would be subtracted from 1 to compute the individual disability weight. This was followed by PTO 2, which asked respondents how many people cured of a particular disabling condition would be considered equivalent to extending the lives of 1000 people. Again, the number of people given would be divided by 1000 and the value subtracted by 1. The values produced by answers to these two questions were required to be the same—if they were not, the respondent was asked to adjust both answers until the scores were equal—despite saving lives and curing disease being two quite different acts, both morally and practically. In 1998, the researchers Trude Arnesen and Erik Nord attended such a weighting session. When any individual wrote 1000 as their answer to PTO 1 (meaning that they judged the lives of disabled individuals as of equal value to non-disabled individuals), they were told that answer “ was regarded as unreasonable...[that] he or she was implying that being disabled is as good as being non-disabled and that there is no need to spend resources on disabled people. It was suggested that he or she should therefore indicate a number higher than 1000.” When polling their fellow participants, 6 out of the 11 felt they were led to answer in a particular way by the experimenter. Such sessions produced, for instance, a weight for quadriplegia of 0.9524, just 4.66% preferable to being dead.<sup>11</sup> The consumer advocate Hilda Bastian called her participation in a similar session, in which participants were asked to imagine having particular

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<sup>10</sup> Arnesen, Trude and Erik Nord. “The value of DALY life: problems with ethics and validity of disability adjusted life years. *British Medical Journal*, 1999. 319: p. 1423

<sup>11</sup> *Ibid.*

disabilities and then rank them by severity, an “Alice in Wonderland” experience, and pointed out that the descriptions of the disabling conditions participants were provided with strayed so far from their actual circumstances as to be unbelievable—every condition was described as lasting for ten years (even pregnancy), and every condition was described as non-fatal (even HIV and Cancer). As she said, “The DALY exercise does not, in fact, value health states: it values what I now think of as ‘altered health states’. People are placing theoretical values on health states which don’t really exist in those terms at all.”<sup>12</sup> Murray, the creator of the metric, “ argued that the health state values should reflect societal judgements of the value of averting different diseases rather than individual judgments of the disutility of the diseases” —that is, that judgements of those around a disabled individual about how their value were what mattered.<sup>13</sup>

In response to these critiques (and the abandonment of the metric as unethical by a multi-country European study in 2003), the method for computing disability weights was altered in 2010. Now, researchers wrote brief, plain-language descriptions of disabling conditions, and household surveys were conducted in five countries—the U.S., Bangladesh, Indonesia, Peru and Tanzania—as well as an open online survey. Survey participants were shown the plain text descriptions for pairs of disabling conditions, and asked to choose which of the two was “healthier.” These data were then used to compute the disability weights for the conditions. In 2013, some conditions were re-surveyed with new language, as well as certain additional conditions being added. Overall, 35% of respondents were American, 64% were highly educated, while 17% had a primary education or less. Those conducting the survey pointed to the fact that responses across countries were highly correlated (except for the weights for HIV and certain

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<sup>12</sup> Bastian, Hilda. “A consumer trip into the world of the DALY calculations: An Alice-in-Wonderland experience.” *Reproductive Health Matters*, 8:15, 2000. pp 113-116.

<sup>13</sup> *WHO Methods and Data Sources*

physical disabilities) as “compelling evidence that contradicts the prevailing hypothesis that assessments of disability must vary widely across samples with diverse cultural, educational, environmental, or demographic circumstances.”<sup>14</sup>

Before proceeding to any philosophical point, it is vital to be clear about an empirical one: DALYs do not, in fact, directly measure the burden of any disabilities. They incorporate data about the *incidence* of various disabling conditions, but their disability weights are calculated based on public opinion surveys, not any actual data about the experiences of individuals with disabilities. The fact that survey data from thousands of laypeople is included, rather than just a few dozen doctors, means that the developers of the metric now incorporates the views of more people, but it does not change the fact that the results are essentially hearsay—that they reflect which conditions a predominantly non-disabled random sample of individuals felt would be worse to have, after being prompted by a brief description of the condition. Small teams of mostly western researchers are writing the descriptions of the disabilities, and certain weights have changed radically from year to year as they have been adjusted—see for instance deafness, whose weight jumped from 0.033 in the 2010 series to 0.215 in the 2013 revision when language related to social isolation was added to the description of the disability<sup>15</sup>. Descriptions are also inconsistent and prone to stereotypes—while the survey designers stated aims were to strip away context and focus on the inherent aspects of the disabilities in question, the descriptions of facial disfigurement state that the individual’s appearance “makes others feel uncomfortable” and that this “causes the individual to avoid social contact,” while the description of intellectual disability states that the individual is unable to raise children without assistance.<sup>16</sup> This is

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<sup>14</sup> WHO Methods and Data sources; Voigt, Kristen. “Disability weights in the global burden of disease 2010 study: two steps forward, one step back?” *Bulletin of the World Health Organization*. 2014. Issue 92, pp.226-228

<sup>15</sup> Salomon et al. “Disability weights for the Global Burden of Disease 2013 study.” *The Lancet Global Health*. Volume 3, Issue 11, November 2015, Pages e712-e723

<sup>16</sup> *Ibid.*



particularly noteworthy given that disabilities, especially mental health conditions, are the subjects of intense stigma, which operates in local “moral worlds” that experimenters may be entirely unaware of. This process of gathering disability weight data therefore risks capturing the impact of such stigma and writing it into global health metrics, thus strengthening and institutionalizing it.<sup>17</sup>

It is particularly worth noting that neither the original formulation of DALYs nor the revised methodology now in use follow in any way the accepted international standards for research into disability, nor do they account for the literature on relative perception of disability by disabled vs. non-disabled individuals. Within the disability context, international research into disability, such as the WHO’s International Classification of Functioning, Disability, and Health, analyzes disability from a functional, empirical perspective. It models the interactions that occur between disabled individuals and their environment, and tallies the negative impact of activities that disabled individuals are unable to engage when these interactions are unsuccessful. “Injuries, illnesses, and developmental problems can be associated with varying degrees of impairment, activity limitation, and limitation in social participation, depending on the affected person’s quality of health care, social and physical environment, and accumulated experience over time. Consequently, one cannot equate specific medical diagnoses or conditions with functional limitation.”<sup>18</sup>

Moreover, the analytical method used to collect the data for the Disability Weights— asking non-disabled people to imagine how bad having a particular disability would be— flies in the face of studies showing that people specifically struggle to accurately mentally project how they would feel under such circumstances, often producing paradoxical responses (in part because

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<sup>17</sup> Hsin Yang, Lawrence et al. “Culture and stigma: Adding moral experience to stigma theory.” *Social Science & Medicine* 64 (2007), pp. 1524–1535

<sup>18</sup> Grosse, Scott D. et al. “Disability and Disability-Adjusted Life Years: Not the Same.” *Public Health Reports*. 2009 Mar-Apr; 124(2): pp. 197–202.

of stigma).<sup>19</sup> Certainly the weights are not remotely reflective of the one group who have arguably the greatest expertise in the subject— people with disabilities themselves, who rate their own quality of life quite highly- in one landmark study, 54.3% of those with moderate to severe disabilities rated their quality of life as good to excellent, a comparable figure to the feelings of those without disabilities.<sup>20</sup> In fact, Murray et al. were aware of this, but chose to deliberately leave the opinions of disabled individuals out of formulating the DALY because, in their view, disabled people rate their own quality of life excessively highly compared to non-disabled people, and it is the views of the latter that are more important—a view that, as one paper noted, would never be regarded as acceptable on issues of, for instance, race or gender.<sup>21</sup>

Perhaps, despite all of these issues, this estimate is good enough—the best we can do given practical resource constraints or lack of more objective measures. But it is worth noting that we do not measure the suffering of any other marginalized group in this way. We do not accept, in any other context, that the life of someone who suffers more is less worth saving. We do not, for instance, measure the “burden” of being a subsistence farmer in sub-Saharan Africa by asking a random sample of several thousand individuals—of whom a substantial majority are neither subsistence farmers nor sub-Saharan Africans— to read brief descriptions of the life of such a subsistence farmer and, say, a Southeast Asian garment worker and decide which is worse. We do not generate “occupational weights” with a dead man at zero and, for instance, an American billionaire set at 1, and then use survey data to suggest that, given their respective levels of hardship, a year of life as a Southeast Asian garment worker is worth 0.5 “Occupationally-Adjusted Life Years,” while a year as a sub-Saharan African subsistence farmer is only worth 0.3. In fact, many people would likely find such an exercise offensive. Yet this does not

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<sup>19</sup> Grosse et al.; Schwartz, Carolyn E. “Response Shift Theory: Important Implications for Measuring Quality of Life in People With Disability.” *Archives of Physical Medicine and Rehabilitation*, Volume 88, Issue 4, April 2007, pp. 529-536

<sup>20</sup> Albrecht, Gary J. and Patrick J. Devlieger. “The disability paradox: high quality of life against all odds.” *Social Science & Medicine* Volume 48, Issue 8, April 1999, pp. 977-988

<sup>21</sup> Grosse et al.

stop us from analyzing and quantifying the experience of people who live in those regions or do those jobs. Rather, we collect hard data on their actual lives, including econometric data, qualitative ethnographic research, and household health surveys that ask the affected people themselves about their experiences. With this data in hand, policymakers are still able to make evidence-based decisions about what course of action to pursue, despite not having a handy metric scoring how much their lives are worth. For the 15% of human beings who have disabilities, however, such an approach is apparently insufficient.<sup>22</sup>

### **DALYs, Suffering, and Immodest Claims of Causality**

Let us then be biosocial about the validity of disability weights, an “approach which demands the reconciliation and occasional disruption of multiple frames of knowledge.”<sup>23</sup> With the history and context now established, my goal is to bring to bear perspectives from outside the International Health establishment on this question, perspectives that the designers and advocates of the DALY do not seem to have taken into account. Several major questions in particular seem to present themselves: what are the unintended consequences of the proposed social action that is the use of DALYs? What ramifications does their connection to neoliberal cost-cutting have? But first, one global health concept in particular must be brought to bear on the concept.

One of the key lessons of the Global Health perspective is that we must beware, in Paul Farmer’s parlance, of Immodest Claims of Causality. “Scholars trained in different disciplines [can] examine the very same topic...and come up with altogether incompatible conclusions. What’s more, these scholars [can] advance such completely discrepant assessments with great

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<sup>22</sup> “World Report on Disability Summary.” The World Health Organization & The World Bank. 2011.

<sup>23</sup> Farmer et al. *Reimagining Global Health* p. 16

confidence.”<sup>24</sup> It is all too easy, in medicine, in social science, and in politics to ascribe consequences to causes based on stereotype or convenience rather than evidence— to say, for instance, that Ebola is spreading because of traditional burial practices, not inadequate hospital supplies— and to miss the actual causes of suffering. Therefore, actually solving problems requires rigorous skepticism about our assumptions.

Murray et al’s rationale for crating DALYs can be described as having four purposes “setting health care priorities, setting research priorities, identifying disadvantaged groups in need of targeted health interventions, and enabling better evaluation of interventions.”<sup>25</sup> But why is a disability-adjusted metric required to address these purposes? The answer would seem to be that it is necessary to measure suffering. We desire not only to preserve individuals’ lives but to improve their quality of life, and we should not ignore the impacts of conditions that cause suffering but not death. These are noble goals, and ones in no way necessarily inconsistent with a disability rights framework. For instance, when the DALY metric was developed, mental health conditions were shown to be a major global contributor to DALYs worldwide, which helped to bring needed attention and resources to addressing mental health issues.<sup>26</sup>

However, in using disability as their measure of suffering, the creators of the DALY are making a quite strong implicit claim—that most or all suffering experienced by people because they are disabled is caused by their medical conditions. This notion is referred to by disability scholars as the Medical Model of Disability.<sup>27</sup> In a nutshell, it argues that the reason that disabled people experience disparities relative to non-disabled people—in rates of poverty, unemployment, homelessness, violent victimization, etc.—is because they have particular physical or mental conditions, and that these disparities can best be alleviated by curing these conditions.

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<sup>24</sup> Farmer, Paul. *Infections and Inequalities: The Modern Plagues*. University of California Press. Kindle Edition. p.23

<sup>25</sup> Farmer et al. *Reimagining Global Health*. p. 227

<sup>26</sup> *ibid*, pp. 226-230.

<sup>27</sup> See, for instance, Bury, Mike, “Illness narratives: fact or fiction?” *Sociology of Health & Illness* Vol. 23 No. 3 2001 pp. 263-285

Certainly this is the model many health practitioners ascribe to—but is this because of evidence, or the “rigidity of habit” as Merton describes it, shutting out perspectives that fail to align with individuals training?<sup>28</sup> If this model holds, then the use of disability as a proxy for suffering in the DALY metric would be justified, as would its approach of presuming that all people with the same disability experience the same level of reduced utility per year regardless of social, cultural, and political context. However, I would argue that this is a substantially immodest claim of causality, and not one borne out by the facts.

Obviously some disabling medical conditions cause significant inherent suffering, regardless of social context; for instance, chronic pain disorders (although even then, whether an individual has access to pain management assistance will make an enormous difference in their quality of life). On the other hand, consider a disability such as deafness. In the 2013 set of disability weights, total hearing loss has a score of 0.215—meaning that a year lived while deaf is judged to have 21.5% less quality than a year lived without disability.<sup>29</sup> Yet deafness biologically causes no inherent suffering whatsoever—no pain, no emotional trauma, and no loss of cognitive function. Deaf people can communicate with each other perfectly well via sign languages, and with the aid of interpreters and technical assistance, they can communicate with anyone that a hearing person can and perform virtually any job that a hearing person can. Large swaths of deaf people, in fact, reject the entire idea that deafness is an impairment at all, arguing that it is a simple biological difference, with deafness being no more inferior to hearing than left-handedness is to right-handedness.<sup>30</sup> Rather, any loss of quality of life from being deaf is due substantially to socially determined factors—being isolated from others, experiencing stigma, and facing marginalization. In fact, the experience of discerning the DALY disability weights bears this out.

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<sup>28</sup> Farmer et al. *Reimagining Global Health*. p.21

<sup>29</sup> Salomon, Josua A. et al. “Disability weights for the Global Burden of Disease 2013 study.” *The Lancet Global Health*. Volume 3, Issue 11, November 2015, pp. e712-e723.

<sup>30</sup> See, for instance, Padden, Carol A.; and Tom L. Humphries, *Inside Deaf Culture*. Harvard University Press, 2005.

When investigators added language to the description of hearing loss emphasizing social isolation between 2010 and 2013, the assigned disability weight for deafness rose six and a half fold between 2010 and 2013, more than any other condition<sup>31</sup>.

In post 2013 Burden of Disease figures, deafness will appear to be a far more prominent problem, and will perhaps become a greater research priority, as Murray's initial mission for DALYs intended. But what kind of interventions does the use of DALYs actually incentivize? Governments may step up efforts to prevent deafness in the fraction of cases where it is caused by other diseases such as meningitis, and might increase funding to efforts to develop a cure for deafness arising from genetic causes. Either of these could cause the absolute number of deaf people in a country to decline, reducing the DALY burden of deafness. Future revisions to the weighting scheme could set a lower weight for deaf people with cochlear implants, but at present no such mechanism exists, and the results of implantation are highly variable from one individual to the next (one study did attempt to calculate the costs per DALY saved of cochlear implants vs. deaf education, but did so by assuming, without evidence, that both an implant and sign language education would move individuals into the "mild hearing loss" category).<sup>32</sup> However, despite the responses that set the weight being clearly driven primarily by concerns about isolation and stigma, interventions designed to address these issues would not affect a country's DALY figures. Providing more interpreters, setting up improved deaf schools, providing vocational training or affirmative action programs for deaf individuals, or encouraging the hearing population to learn sign language—all of these would greatly improve the quality of deaf people's lives, but none of them would make them stop being deaf (and unlike with some other disabilities, the weights for hearing loss vary only on the basis of severity), so the figures would not change.

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<sup>31</sup> Ibid.

<sup>32</sup> Saunders, James E. et al. "Cost Effectiveness of Childhood Cochlear Implantation and Deaf Education in Nicaragua: A Disability Adjusted Life Year Model." *Otology & Neurotology*, Issue: Volume 36(8), September 2015, pp. 1349–1356

This is in no way unique to deafness. Quadriplegia for instance, has a substantial weight— 0.369 for a treated spinal cord injury at the neck ( though this is down substantially from its pre-2010 DALY weight of 0.9524).<sup>33</sup> Let us consider, however, a specific quadriplegic person: H, my mentor and former supervisor. Because of government policies in place in the United States in general and Massachusetts in particular, he lives his own apartment, has a voice-operated computer and a chin-stick-operated electric wheelchair, and has personal care attendants to feed him and attend to his hygienic needs. When he enters a public building, he can be relatively assured because of federal law that it will be wheelchair accessible. He works full time, and has earned three master's degrees, thanks in part to further federal laws requiring educational access. His life is by no means perfect—he is still subject to stigma, and in order to get most of these services he is obliged to earn virtually no income. However, a year in his life will be far more pleasant than the life of an identically quadriplegic person in a developing country who may be “treated,” but likely has no access to these services and legal protections.

In fact, a major empirical field study by Allotey et al. comparing the experiences of quadriplegic people in Cameroon and Australia found massive quality of life differences, owing to such issues as vast disparities in the quality of hospitals, rehabilitation systems, wheelchairs, and other such Staff, Stuff, Space, and Systems issues. The authors concluded that “The underlying assumptions of the DALY, which ignore context in the assessment of the burden of disease, risk exacerbating inequalities by undervaluing the burden of disease in less-developed countries.”<sup>34</sup> And yet, if Cameroon chose to improve the quality of its disabled citizens in the same way that disabled Americans' lives have been improved, its DALY figures would not change. And because DALYs are the statistic used to determine if public health interventions

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<sup>33</sup> Salomon et al; Arnesen and Nord

<sup>34</sup> Allotey, Pascal et al. “The DALY, context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon.” *Social Science & Medicine*, Volume 57, Issue 5, September 2003, Pages 949-958

are cost effective, such interventions are inherently likely judged to be poor uses of healthcare funds.

In fact, upon considering the social circumstances faced by many individuals with disabilities—intense stigma, social discrimination, constrained choices in where to live, what to do, and whom to associate with, and often limited ability to make one’s own decisions—the framework that seems most apt to describe the suffering associated with disability is that of structural violence. “Such suffering,” in Paul Farmer’s words, “is structured by historically given (and often economically driven) processes and forces that conspire—whether through routine, ritual, or, as is more commonly the case, the hard surfaces of life—to constrain agency.”<sup>35</sup> Structural violence has a substantial impact on who gets access to health care, it worsens health outcomes, and it causes injury, producing disparities between those subjected to structural violence and those who are not.<sup>36</sup> In the United States, to say nothing of the developing world, people with disabilities are 1/4th as likely be employed as non-disabled people – in part because they are subject to pernicious employment discrimination, as shown by fictitious resumé studies.<sup>37</sup> People with disabilities are more than twice as likely to be homeless as people without disabilities<sup>38</sup>, largely because so little housing is both affordable and accessible— in my own work in disability housing advocacy, we found there were more than 2,000 people, all homeless or housing insecure, on a waiting list for fewer than 500 vouchers, because finding market-rate housing that met their access needs was next to impossible. Over a million disabled Americans—a rapidly-growing 15% of whom are under 65—live in nursing homes, legally barred from working and with severely

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<sup>35</sup>Farmer et al. *Reimagining Global Health*. p.30

<sup>36</sup> Farmer, Nizeye, Stulac, and Keshavjee. “Structural Violence and Clinical Medicine,” *PLOS Medicine*, Volume 3, Issue 10. October 2006. 1686-1691

<sup>37</sup> “Persons with a Disability: Labor Force Characteristics Summary,” U.S. Bureau of Labor Statistics, 6/21/17.; Ameri, Mason, et al. “The Disability Employment Puzzle: A Field Experiment on Employer Hiring Behavior.” National Bureau of Economic Research, September 2015.

<sup>38</sup> Diament, Michelle. “More Than Two-Fifths Of Homeless Have Disabilities.” [DisabilityScoop.com](http://DisabilityScoop.com), 7/16/09



constrained freedom of choice.<sup>39</sup> Finally, emphasizing the *violence* in “structural violence,” people with disabilities make up between 1/3 and 1/2 of all those killed by police.<sup>40</sup>

These are the factors, far more than inherent biology, that reduce the quality of life of individuals with disabilities—that make them sicker, that traumatize them, and that shorten their lives. All of this, moreover, is true 27 years after the passage of a civil rights law that dramatically *improved* the social standing of individuals with disabilities. It is for this reason that the Disability Rights movement has by and large rejected the Medical Model of Disability in favor of the Social Model of Disability, which holds that bodies and minds naturally vary, and when society's institutions are constructed to exclude people with particular bodily or mental differences, it is that act of structural violence that disables people. As Partners in Health, among many others, has shown, healthcare interventions can be targeted to combat structural violence, with powerful, often lifesaving results. However, nothing about the DALY captures these aspects of the disability experience—in fact, by having fixed weights for disability conditions that are not ameliorated by care, it actively refuses to consider them.

### **Cost Effectiveness and Neoliberalism**

Even if it is built upon immodest claims concerning the causes of suffering experienced by disabled people, DALYs would likely still be a defensible metric if their sole purpose was to measure the cumulative effect of particular conditions. It is useful to have some number for, say, the effect that depression is having worldwide—and, even if there are serious flaws in how the weight is derived, we can still see how the total burden figure shifts over time and derive some utility from seeing if it is rising or falling in response to policies and social forces. However, it is vital to put DALYs in their proper context in the sociopolitical history of international health. Murray explicitly intended the metric to be used to inform resource allocation decision-making,

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<sup>39</sup> Irvin et al. “Pathways To Independence: Transitioning Adults

Under Age 65 From Nursing Homes to Community Living.” *Mathematica*, 2015.

<sup>40</sup> Perry, David M. and Lawrence Carter Long. “The Ruderman White Paper on Media Coverage of Law Enforcement and Disability.” March 2016.

and he did not come to that conclusion in a vacuum. Rather, the coming out party for the DALY was in the 1993 World Development Report: Investing in Health. On the one hand, the report marked a moment when the World Bank would become more involved in funding healthcare programs, rather than purely pushing for structural adjustment. On the other, the programs the report promoted shifted dramatically away from the Alma-Ata principles of Primary Care for all in favor of a thoroughly market-based approach, in which health interventions would be evaluated on strict grounds of cost effectiveness. DALYs enabled this approach, providing the numerators with which all health programs could be judged. As a result, every cost-effectiveness calculation would be performed with the lives of individuals with disabilities discounted.<sup>41</sup>

In fact, the fact that DALYs do not accurately measure disability does not mean that the metric does not serve a very specific purpose. Specifically, the DALY can be framed as an exercise in Biopower, a force identified by Michel Foucault which is “at work...any time quantification of life leads to categorization of life.” The social nature of illness, both physical and especially mental, varies substantially within cultures and societies—and conditions which are seen as tremendously disabling in some contexts may be seen as normal (or even desirable) in others. Such subjectivity would make it impossible for global institutions to make universal comparisons or regulate the policy decisions of national and subnational actors. The DALY, then, serves to Discipline both nations and the individuals within them by imposing a Western, culturally constructed notion of Disability on them. “Observing, reforming, converting, and categorizing” the variety of human negative health experience into a series of measurable boxes, bringing “life and its mechanisms into the realm of explicit calculations,” and thereby creating path dependence towards certain types of actions that follow naturally from those calculations.<sup>42</sup> In particular, Foucault locates the contemporary notion of disability as rooted inherently in capitalism, which forces distinctions not only between “the rich and the poor, healthy and sick, strong and

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<sup>41</sup> Farmer et al. *Reimagining Global Health*, pp. 235-240

<sup>42</sup> Farmer et al. *Reimagining Global Health*, pp. 25-30.

weak, but also between the more or less utilizable, more less amenable to profitable investment, those with greater or lesser prospects for survival , death and illness, and with more or less capacity for being usefully trained.” With DALYs, societies are pushed implicitly to consider its citizens lives based on their capacity for productivity—a distinctly neoliberal idea. <sup>43</sup>

As Salman Keshavjee writes about neoliberalism and its effect on values, “by making the social world subject to economic considerations—rather than the economic being one part of the social realm—something significant happens: the market becomes the arbiter of all things social and moral.”<sup>44</sup> I would argue that this is precisely what happened with the DALY with regard to disability. If we were approaching healthcare decision making from a primarily ethical standpoint, for instance, Rawls’ Theory of Justice, both the disadvantaged social position of individuals with disabilities and the fact that—as DALYs themselves are based around— disabled individuals experience greater average suffering, then “from an ethical point of view it could be forcefully argued that priority should be given to the disadvantaged person rather than to the perfectly healthy person--exactly the opposite of what is implied in using the DALY formula for resource allocation,” as Anand and Hanson put it.<sup>45</sup> The logic of DALYs inverts our ethical sensibilities by saying that the more individuals suffer, the less it is worthwhile to save their lives. Moreover, it Rationalizes this counterintuitive ethic, in the Weberian sense of the word—taking a prejudicial social intuition about a marginalized, stigmatized group (recall the reaction of the experimenters to participants rating disabled and non-disabled people’s lives equally) and formalizing it to appear standardized, scientific, and empirical, and helping to erect an “iron cage” of bureaucracy in which moral judgements can be subsumed in favor of impersonal calculations.<sup>46</sup>

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<sup>43</sup> Foucault, Michel. “The Politics of Health in the Eighteenth Century” in *The Foucault Reader*. Pantheon Books, 1984 .

<sup>44</sup>Keshavjee, Salmaan and Paul Farmer. *Blind Spot : How Neoliberalism Infiltrated Global Health*. University of California Press, 2014.

<sup>45</sup> Anand and Hanson

<sup>46</sup> *Ibid.*

## The DALY Ethos in Action: Healthcare Rationing

One commonly mounted defense of the use of DALYs as a metric is that they would not, in fact, actually be used in ways that devalue the lives of individuals with disabilities—that there is simply a need for a metric that deals effectively with non-fatal adverse health outcomes, and that disability weights are the most efficient means of doing so. Such an argument puts its faith, in essence, in ethical standards: that even though the logic of DALYs naturally suggests that the lives of people with disabilities are worth less than those without disabilities, and that the rationale for the use of DALYs is that they are necessary to make cost-effective funding allocation decisions, governments and other health-sector actors would be restrained by ethical principles from actually acting in ways that sacrificed people with disabilities in favor of non-disabled people. Such an argument, however, becomes hard to believe when arguably the most celebrated moral philosopher of the modern era has spent his much of his career explicitly championing the devaluation of the lives of people with disabilities in precisely the terms implicit in the logic of DALYs.

Peter Singer is one of the most influential figures in contemporary philosophy. His 1975 book *Animal Liberation* is credited with launching the contemporary animal rights movement, while his 1972 essay "Famine, Affluence and Morality" argued powerfully for the immorality of the continued existence of hunger in a world that also contained extreme wealth.<sup>47</sup> In recent years, his books *The Life You Can Save* and *The Most Good You Can Do* have been instrumental in launching a global movement known as Effective Altruism, which seeks both to increase charitable donations and to channel them to institutions whose interventions are most cost-effective (often defined in DALY terms).<sup>48</sup> But he is also notorious among disability rights

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<sup>47</sup> Vuillamy, Ed. "Peter Singer" *The Observer*, 2/15/09.

<sup>48</sup> Skelton, Anthony. "The ethical principles of effective altruism." *Journal of Global Ethics*, 12:2, 8/07/16, pp. 137-146.. ; Thompson, Derek. "The Greatest Good." *The Atlantic*. 6/15/15

activists for arguing that the lives of individuals with disabilities are quantifiably less valuable than those without disabilities—to the point that homicide against infants with disabilities is sometimes not ethically wrong or even ethically preferable. As he put it in his 1993 book *Practical Ethics* (following up on his 1985 book *Should the Baby Live? The Problem of Handicapped Infants*):

Parents may, with good reason, regret that a disabled child was ever born...When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if killing the haemophiliac infant has no adverse effect on others, it would, according to the total view, be right to kill him...It may still be objected that to replace either a fetus or a newborn infant is wrong because it suggests to disabled people living today that their lives are less worth living than the lives of people who are not disabled. Yet it is surely flying in the face of reality to deny that, on average, this is so...the main point is clear: killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all.<sup>49</sup>

I believe most people, myself certainly included, would recoil at any chain of reasoning that leads to the conclusion that killing any infant is not morally wrong. However, upon further examination, Singer's chain of logic within this passage is fundamentally the same as that underlying DALYs. It asserts that the lives of disabled people are inherently less worth living, what-

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<sup>49</sup> Singer, Peter. "Taking Life: Humans" in *Practical Ethics*. Cambridge University Press. 1993.

ever they may think about it. It weights the life of a disabled individuals against that of a non-disabled individual, finding greater net utility from life for the latter. It ignores any specific characteristics of the individuals in question in favor of considering disabled people in aggregate vs non disabled people in aggregate. Finally, it considers a society-wide maximization function, and determines that based on the metrics at hand, society will be better off with fewer disabled people and more non-disabled people. The only difference is that it then takes the argument to its logical extent: if maximizing the utility metric is ethically good, and a society that replaces disabled people with non-disabled people maximizes the metric, then actions which serve that replacement, including infanticide, become morally justified.

This is a philosophy text, but such ideas play out in reality. In the 1990s Maurice King argued that children in Rwanda should be allowed to die to ease population pressures. His targets were sick children rather than congenitally disabled ones, but the logic was fundamentally similar to Singer's—that if the deaths of some children enabled a greater number to achieve greater welfare, this would be justified from a utilitarian point of view (this also proved to be an immodest claim of causality—as Luc Bonneux demonstrated, birth rates, not infant mortality rates, were what almost determined population levels).<sup>50</sup> Meanwhile, homicides against disabled children are a very real problem—a 2017 Ruderman Family Foundation white paper found 219 instances between 2011 and 2015 of disabled people being murdered by their parents or caregivers (likely an undercount). Often, both those who committed the killings and the media outlets the covered the cases described them as “mercy killings,” emphasizing the diminished quality of life experienced by the disabled individuals to argue that killing them was therefore not wrong. Often these arguments produced significantly reduced sentences—as in the case of autistic 14 year old Alex Spourdalakis, whose mother and godmother poisoned him with sleeping pills and

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<sup>50</sup> Bonneux, Luc. “Rwanda: a Case of Demographic Entrapment. *Lancet* 344, no. 8938 (1994): 1689-1690.

then stabbed him to death. They were sentenced to three years for involuntary manslaughter.<sup>51</sup> In a system which weights disabled people's lives as fractionally important, it is scarcely surprising that their deaths are seen as fractionally tragic—and their killers receive only fractional sentences.

The tight link between Singer's reasoning and that of DALYS—and the policy consequences of both—can be most clearly seen in his 2009 New York Times article *Why We Must Ration Health Care*, in which he explicitly argues that adjusted life year metrics should be used to deny individuals lifesaving health care, with disabled individuals in particular at the back of the line. (His specific reasoning in the article uses QALYs rather than DALYs, but both metrics use disability weights in a fundamentally similar manner):

One common method is to describe medical conditions to people — let's say being a quadriplegic — and tell them that they can choose between 10 years in that condition or some smaller number of years without it. If most would prefer, say, 10 years as a quadriplegic to 4 years of nondisabled life, but would choose 6 years of nondisabled life over 10 with quadriplegia, but have difficulty deciding between 5 years of nondisabled life or 10 years with quadriplegia, then they are, in effect, assessing life with quadriplegia as half as good as nondisabled life... This is the basis of the quality-adjusted life-year, or QALY, a unit designed to enable us to compare the benefits achieved by different forms of health care... a treatment that extends the lives of people without disabilities will be seen as providing twice the value of one that extends, for a similar period, the lives of quadriplegics. That clashes with the idea that all human lives are of equal value. The problem, however, does not lie with the concept of the quality-adjusted life-

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<sup>51</sup> Perry, David. "The Ruderman White Paper on Media Coverage of the Murder of People With Disabilities by Their Caregivers." Ruderman Family Foundation, March 2017.

year, but with the judgment that, if faced with 10 years as a quadriplegic, one would prefer a shorter lifespan without a disability.<sup>52</sup>

Singer is right that these are the logical ramifications of DALYs and QALYs—that based on their underlying methodological assumptions, the lives of people with disabilities are valued less, and that treatments that save those lives are worth less. The conclusion he draws is that these metrics do in fact demonstrate that disabled people’s lives are worth less, that public systems of health insurance should ration their treatment dollars on a cost-effective per-DALY basis, and that they should deny treatments whose per DALY costs are too high; the result being that disabled people, who by this reckoning are worth less, would be frequently denied healthcare.

The result of such a system, if implemented, would be the widespread suffering and death of disabled individuals—and indeed, such proposals regularly play out in the policy arena. In Britain, healthcare rationing has hit the NHS hard, with much of the burden specifically targeted at people with disabilities—mental health services were delayed or eliminated, children were issued substandard wheelchairs, hip and knee replacements were cut back, and one 22 year old woman with leukemia died after a local clinical commissioning group ruled that a treatment with a 50% chance of curing her was too expensive to attempt.<sup>53</sup> Disability benefits were also slashed, with more than 160,000 people losing benefits—and the result of the two, by one estimate, was 30,000 excess deaths of elderly and disabled people.<sup>54</sup> In the U.S., protests by disability advocates were a major part of defeating federal Medicaid cuts that could have led millions of people to lost health care, but state level programs for disabled people are now being

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<sup>52</sup> Singer, Peter. “Why We Must Ration Health Care.” *The New York Times*, 7/15/09.

<sup>53</sup> Campbell, Dennis. “NHS rationing ‘is denying patients care’ as cash crisis deepens.” *The Guardian*. 12/8/15

<sup>54</sup> Pasha-Robinson, Lucy. “Disabilities minister quietly ‘blocks PIP benefit payments to 160,000 people.’” *The Independent*, 2/24/17; Glaze, Ben. “Social care scandal as Tory cuts ‘led to the deaths of 30,000 people’ - and it’s going to get worse.” *The Daily Mirror*. 2/17/17



slashed in Oklahoma, Iowa, and Maine.<sup>55</sup> If the dollars from such cuts were re-directed into programs for non-Disabled people, it is a virtual mathematical certainty that DALY metrics would show increased cost-effectiveness. Governments, it seems, are following the rationing rationale.

### **Care Gets No Credit: Rehabilitation and the Act of Caring**

Aside from the basic devaluing of disabled people's lives, the rationale for cuts provided by the DALY rests in part on a common problem throughout the international health establishment: insufficient value being placed on the provision of care. As Arthur Kleinman puts it, "If caregiving is absent from the political and economic discourse on health care, then nothing but institutional and monetary issues seem to matter. Even questions of "quality" in health care become distorted."<sup>56</sup> In a disability context, care makes all the difference in quality of life, raising standards of living and enabling even significantly disabled individuals to be both independent and content. Even when care is provided by family members, government support can be critical, such as the provision of respite services that can take the pressure off caregivers at critical moments.<sup>57</sup> Meanwhile, access to professional caregiving can radically improve the lives of disabled individuals, particularly under Personal Care Attendant systems where the disabled individual is the employer of record and controls their own care<sup>58</sup>. The use of DALYs, however, discourages all such programs by not accounting for the ways in which the provision of caring improves individuals subjective experience. Of particular concern is the insensitivity of the metric to rehabilitation services, despite their ability to moderate if not eliminate many of the symptoms

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<sup>55</sup> Perry, David M. "States of Neglect: Oklahoma, Iowa, and Maine Are Failing Disabled Residents." *The Nation*, 11/14/17.

<sup>56</sup> Kleinman, Arthur. "Caregiving as moral experience," *The Lancet*, Vol 380. 11/3/12. pp. 1550-1551

<sup>57</sup> Chan, Jeffrey B. and Jeff Sigafos. "Does Respite Care Reduce Parental Stress in Families with Developmentally Disabled Children?" *Child and Youth Care Forum*. Volume 30, Issue 5, pp 253–263. October 2001.

<sup>58</sup> Kane, Rosalie A. "Long-Term Care and a Good Quality of Life: Bringing Them Closer Together ." *The Gerontologist*, Volume 41, Issue 3, 1 June 2001, pp. 293–304; Doty, Pamela, Judith Kasper and Simi Litvak. "Consumer-Directed Models of Personal Care: Lessons from Medicaid," *The Milbank Quarterly*, Vol. 74, No. 3 (1996), pp. 377-409.

upon which the presumed severity of many disabilities rests.<sup>59</sup> In Dr. Kleinman's words, "No cost-benefit evaluation of health care can leave caring out and still be viewed as an adequate assessment."<sup>60</sup>

### **What Could We Do Instead?**

At this point, it is hopefully clear that the DALY as constructed had fundamental flaws. While revisions to the formula since 2010 have addressed many other ethical and practical critiques of the metric, the use of disability weights calculated based on the opinion of people without disabilities seems inherent to the identity of the DALY. Such a weighting scheme is built on immodest claims of causality. It ignores the real circumstances and the views of people with disabilities. It rationalizes stigma and stereotype, and enabled neoliberal cost-cutting. It ignores at best and contributes at worst to structural violence. It undergirds calls for healthcare rationing. And above all, it fundamentally devalues the lives of people with disabilities.

However, the four needs identified by Murray—"setting health care priorities, setting research priorities, identifying disadvantaged groups in need of targeted health interventions, and enabling better evaluation of interventions"—still exist. If DALYs were to be eliminated, something would need to replace them. Fortunately, there are several ideas out there that would fulfill the same role of creating a metric without any of the problems of DALYs. One potential answer came this past October from the world of Palliative Care. This branch of medicine in particular is especially hard done by DALY-based analysis, as the value it provides—reducing the pain of the end of life—neither prevents disability nor usually extends lifespan. In a major report on the issue, dozens of eminent physicians called among other things for the creation of a Suffering-Adjusted Life Year (SALY), using hard data on the suffering experienced by people experiencing various medical conditions and giving credit within the metric for interventions that alleviate that

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<sup>59</sup> Jelsma, Jennifer, Willy De Weerd and Paul De Cock. "Disability Adjusted Life Years (DALYs) and rehabilitation." *Disability and Rehabilitation*. 07/07/02. pp. 378-382.

<sup>60</sup> Kleinman, Arthur. "Care: in search of a health agenda" *The Lancet*, Vol 386, 7/18/2015. pp. 240-241

suffering. If broadly defined, such a metric would do a great deal to more fairly and accurately define disability, since the interventions that improve quality of life for disabled individuals who have access to them could be modeled as reducing suffering.<sup>61</sup>

The most promising approach, however, may be that developed by Daniel Mont and Mitchell Loeb in their 2008 World Bank paper “Beyond DALYs: Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities.” This approach seeks to replace DALYS with a metric built on the International Classification of Functioning, the WHO’s primary analytical document on the actual lived experience of individuals with disabilities. This is an output-based metric; it measures well-being by what individuals are capable of doing given their level of supports, not by their diagnosis (let alone other people’s opinion of it.) Disability is modeled as a restriction in the ability of the individual to participate in activities given their environment and bodily attributes. The two metrics they develop, the Activity Limitation Score and the Participation Restriction Score, track individuals’ functional abilities across a weighted series of activities that are grouped into domains—ALS without assistive devices, and PRS with them. These metrics are sensitive to public health interventions, and in testing them in Zambia the authors were able to observe the shifts in the metrics given the presence or absence of particular interventions. In particular, the gap between the ALS and the PRS can measure the extent to which assistive programs increase well-being, while shifts in ALS specifically can capture the impact of purely medical interventions such as surgeries.<sup>62</sup> With further time and development, these metrics could be slotted into a DALY-like metric, one which would be able to measure the loss of utility by disabled people relative to healthy ones,

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<sup>61</sup> Knaul, Felicia Marie et al. “Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report.” *The Lancet*, 10/12/17.

<sup>62</sup> Mont, Daniel and Mitchell Loeb. “Beyond DALYs: Developing Indicators to Assess the Impact of Public Health Interventions on the Lives of People with Disabilities.” *The World Bank Special Discussion Paper*. May 2008.

but also one which would measure their loss of utility relative to other people with the same disability who were receiving better health care. In so doing, we can integrate global health perspectives into the international systems of public health, and make our decisions both more ethical and more effective at truly improving the state of the world.

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