

Measuring health and disability

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Disability-adjusted life years (DALYs)—a frequent indicator for assessment of the relative effects of public-health interventions—explicitly incorporate disability. This Viewpoint will argue, however, that the notion of disability embodied in DALYs does not accord with that in WHO’s International Classification of Functioning, Disability, and Health (ICF). Underlying this inconsistency is the basic issue of what is meant by health and disability. The result is that DALYs are a poor indicator of the effect of public-health interventions that improve the lives of people with disabilities. An argument can be made that DALYs are better suited for assessment of the effect of programmes and policies aimed at prevention of disabilities, but even in this case their approach to measurement of disability needs to be enhanced.

Disability and health are difficult concepts to define and measure. In fact, the appropriate definition of disability depends on the reason behind its measurement. Thus, when monitoring or assessing public-health interventions, having a clear definition of disability is very important. Before the advent of DALYs (and the earlier but related idea of quality-adjusted life years [QALYs]), health-outcome measures typically relied on mortality (an exception was the method of disability-free life expectancy and its complement, the number of years lived with a disability).¹ In view of the wide range of effects that various health conditions can engender, the approach of using only mortality was judged inadequate. Injury and disease can cause many disabling conditions that have substantial effects on the quality of life. DALYs were developed to combine both mortality and these other effects into one measure.

Basically, DALYs are calculated by adding together years lost from premature mortality and the loss experienced by living a certain number of years with a disability (see panel for a full explanation). According to the World Bank’s 1993 global burden of disease study,² DALYs have three major objectives: “to facilitate the inclusion of nonfatal health outcomes in debates on international health policy, to decouple epidemiological assessment from advocacy so that estimates of the mortality or disability from a condition are developed as objectively as possible, and to quantify the burden of disease using a measure that could be used for cost-effectiveness analysis”. The overriding goal was to create a measure that could help enhance the allocation of resources battling poor health.

This goal is very important. Developing countries generally have many competing needs and scarce resources, forcing governments to make hard decisions about how best to improve the lives of their citizens. Having a transparent, well-understood, and practical

way of assessing their options is essential for understanding the trade-offs they face. However, an indicator that does not properly embody the intended goals can build in systematic bias against achieving them.

Critics claim that DALYs devalue the lives of disabled people.^{3–5} A year lived with a disability is counted as something less than a year lived without one. Conversely, saving the life of an individual with a disability does not improve the summary measure of health as much as saving the life of a person without a disability. The fear is that this fact will drive resources away from disabled people, making them even more vulnerable and disadvantaged than they already are in many societies.

Panel: Disability-adjusted life years

Originally, health outcomes were assessed by years of life lost, but this measure ignores the effects of disability. No credit was given to interventions for reducing the amount of time spent living with a disabling health condition.

The introduction of disability-adjusted life years (DALYs) attempted to rectify this omission by combining years lost from premature mortality with the loss experienced by living with a disability. This factor is expressed as a unit of time and is calculated by multiplying years spent living with a disabling condition that results from a particular disease or injury by an associated disability weight. For example, consider a woman who acquires a chronic illness that leads to her living 10 years with a condition that has a disability weight of 0.4 and then dying 10 years prematurely. Her loss in health would be 14 DALYs—ie, the sum of the 10 years of lost life plus the four-year loss (10×0.4) from the disabling condition.

DALY weights are derived by expert panels making hypothetical trade-offs between the lives of people with different health conditions and an improvement in the health of people with various conditions. They are meant to capture the desirability of the general population of living in a particular health state.

Quality-adjusted life years (QALYs) also attempt to capture mortality and life with a particular health state, and they use their own weighting system. Weights for QALYs are determined by the subjective valuations of patients living with various disorders based on their ability to function in different ways, such as mobility, self-care, and usual life activities. QALYs are mainly designed to assess the trade-offs between health interventions that lead to a longer survival time with a reduced health-related quality of life compared with those that lead to a shorter survival time with a better health-related quality of life.

The irony here is that widespread use of DALYs has arguably raised the profile of disability. Before this indicator was derived, measures of mortality that were typically used did not account for disability. However, although DALYs take into account the prevention of medical conditions associated with disability, critics argue that by counting a year lived with a disability as less than a full year, the effect is to make the lives of people with disabilities worth less than those of people without disabilities.

Is the manner in which disability is combined with mortality in the calculation of DALYs an issue? If one is focused solely on the prevention of disability, tying disability to medical disorders is not troublesome. With DALYs as an indicator (versus mortality), an intervention would get credit for prevention of disability. Furthermore, DALYs were never meant to capture the worth of an individual's life. They were intended to show the loss of health or, more directly, the population's feelings about the desirability of living a year with various conditions that affect health. Incorporation of these preferences into decisions on how to allocate health resources seems reasonable.

The difficulty lies in how DALYs encapsulate disability and how disability relates to health. Currently, summary health measures portray disability as a medical condition that rests within the individual. To have a disability is therefore to necessarily have poorer health. In a sense, disability is viewed as an expression of the poor health associated with a particular illness, such as diabetes, polio, or epilepsy.

The social model of disability holds a very different view, believing that disability arises from the interaction of an individual's functional status with the physical, cultural, and policy environments.^{6,7} If the environment is designed for the full range of human functioning and incorporates appropriate accommodations and supports, then people with a non-normative functional status would not be disabled in the sense that they would be able to fully participate in society.

This approach has, to a certain extent, been incorporated into the theoretical model underlying the ICF. This guideline from WHO separates the notion of functional limitation from disability. Further, functional differences are measured along three different domains: (1) body structure and function; (2) activities; and (3) participation. Body function relates to the physiological and psychological functions of body systems whereas body structures are defined by the ICF as "anatomic parts of the body such as organs, limbs and their components". This domain assesses very specific capabilities, for example, being able to lift one's arm over one's head or articulate speech sounds. Activities and participation pertain to individual functions versus particular body functions or structures. Activities tend to be less complex, such as getting dressed or feeding oneself; participation generally

refers to higher order activities that are integral to economic and social life, such as being able to attend school or hold a job.

After presenting a detailed classification of a comprehensive set of functional limitations, the ICF then incorporates the social model by including information on how an individual's functional capabilities are affected by the environment they face. For example, a given classification within the body function domain will not necessarily translate into an activity or participation limitation if the environment accommodates a person's functional status. The ICF thus has separate classifications for activity and participation limitations in the current environment, a standard environment, and an optimal environment.

This view of disability is very different from the one embodied in DALYs. This indicator does not assume explicitly that a given medical condition always decreases health by the same amount. However, by applying an average weight to people with that condition, DALYs do not take into account how that condition affects individual lives. That is, the disability weight is applied equally to people with the same condition.

Disability weights are calculated by age, sex, and region. In principle, if global burden of disease estimates were calculated for detailed population subgroups (eg, by income, employment status, educational attainment, etc), the disability weight could capture some differences in the impact of health disorders across these subgroups. In general, though, this method is not used.

With the ICF approach, the medical diagnosis does not matter; however, functional status does—in particular, how an individual's functioning interacts with the environment to create disability.⁸ Besides, two people with the same illness do not necessarily have the same stream of health states, nor do these states necessarily affect their functional capabilities similarly. This variability might be either attributable to treatments or rehabilitative services they have received or simply because illnesses sometimes manifest differently. Therefore, the relation between a medical disorder and presence of a disability can vary greatly from one country to another and from one individual to another.^{9,10}

Functional status is not necessarily tied to a particular illness in a straightforward manner. Difficulties with speaking can stem from a stroke, autism, or having a stutter. The effect on someone's life comes not from their functional status—in this case their mode of communication—but from the extent to which that mode of functioning has been accommodated. The same is true for people with disabilities not related to an illness, such as a child who is born deaf. The level to which this condition imposes restrictions on an individual's life depends on the family's and community's ability to use sign language, for example.

(Of note, most disabilities arise in adulthood.^{11,12} Findings of a survey in Nicaragua showed that only 9% of disabilities were present at birth.¹³)

The key point is that if disability is tied to a medical disorder independent of the environment the individual is living in, then any public-health expenditure that mitigates the effects of a change in functional status resulting from a medical condition is not seen as improving public health. DALYs do provide a measure of the benefits of preventing disabilities but they do not encompass the benefits of addressing needs that people with different functional statuses might possess.

This point brings us to the question of what is health? According to the official WHO definition, health is a state of complete physical, mental, and social well-being, not merely the absence of disease—or by extension, functional limitations. Consider an individual without a leg. What if they have no loss in life expectancy and need no medical interventions? Suppose he or she uses a prosthesis or wheelchair and participates fully in society with no substantial restrictions: work, school, marriage, religious and civic activities, leisure activities, etc. On what basis can we say that this individual is not healthy? And if they are not healthy, then what is the reason for having so-called good health and why is it valued? Moreover, who is entitled to make that determination?

Advocates of DALYs point out that—based on survey data from around 100 000 respondents in more than 60 countries—people have strong preferences not to have certain health conditions that they perceive as being associated with functional limitations (Mathers C, World Health Organization; personal communication). Since society deems these conditions undesirable, and since they are at least to some extent preventable by health services, allocation of resources should take this point of view into account. Again, DALYs are not meant to capture the worth of a life to the person living it, but rather its desirability.

The question then remains, how is this desirability quantified and who gets to do it? DALY disability weights are a numerical scale representing the relative severity of the outcomes of different medical disorders, with zero being perfect health and one being death. Separate weights are calculated based on age, sex, country, and access to treatment. Within these groups, however, the relation between a medical condition and the desirability of living with the associated disability is the same irrespective of the environment in which an individual lives and the supports and accommodations they receive. As stated in the previous section, this measure is at odds with the social model of disability, which informs the basis of the ICF.

Of course, the relative severity of the weights is most important, not some absolute measure of the desirability or quality of life associated with a particular illness. The goal, after all, is to allocate resources to address those

disorders that society finds most debilitating. Ranking of disability weights for various conditions is fairly stable across countries.¹⁴ However, does ordinal consistency necessarily imply that rankings are correct? To address this question, we must review the way in which they are created.

The first step in establishing disability weights was to assemble an expert charged with the task of assessing various medical disorders. This group included health professionals along with demographers, economists, sociologists, and statisticians. The health professionals were expected to have worked with people living with various medical conditions and, therefore, to have a good sense of the effects of a wide range of diseases. Panel members were asked to provide their valuation of the severity of the perceived disability associated with a list of medical disorders. Basically, the method relied on panel members making hypothetical trade-offs between the lives of people in good health relative to those with a particular condition or between an improvement to good health of people with that condition. As such, the method is very much based on a definition of disability as a functional deficit that resides in an individual, rather than as a functional status that interacts with the environment.

Based on the expert panel's valuations, diseases were grouped into six classes of severity. These classes were assigned a weight based on the panel's own experiences and findings of a review of available epidemiological research. Therefore, the validity of DALYs rests in large part on the validity of the panel's composition and on that of the underlying assumptions.

No effort was made to include individuals with disabilities in the panel. Since these are the people who understand what living with a disability entails, any valuation of how a given functional status affects a person's life should incorporate their views. After all, these individuals have personal experience living with that particular status. Besides, medical experts might well be biased in the sense that they tend to view disability as a disorder to be cured rather than a functional status that needs to be accommodated. For that reason, critics of DALYs have suggested including more people with rehabilitative experience.¹⁵ Moreover, research shows that non-disabled individuals view the functioning status of disabled people as having a larger effect on quality of life than people with disabilities do.⁵

Defenders of DALYs reject this argument and propose the following: people born with disabilities do not have the experience of living without a disability so they will have difficulty valuing the difference between living with and without a disability (although as noted earlier, this group represents only a small proportion of people with a disability). Furthermore, people whose onset of disability takes place after birth adjust to their situation and, thus, value the loss stemming from their disability

relative to their expectations of living with such a condition not relative to living in so-called good health. In that sense, they have their own particular bias. Moreover, if people without disabilities were willing to forego a certain number of years lived in order to avoid a particular disability then that could be an appropriate way to value the worth of an intervention preventing that disability. A primary aim of DALYs, after all, is to decide how to spend the public's resources on affecting their health outcomes.

Once again, this line of analysis derives from viewing disability as a medical condition that creates a deficit in an individual, rather than simply changing his or her functional status—a status that affects a person's life depending on the environment they live in, as the ICF acknowledges.

How valid are disability weights if they stem from a view of living with a different functional status based on misconceptions about living with it? What if functional status is conditional on the environment? If disability weights truly took into account life as a person with a disability then DALYs lost could be reduced by making accommodations and by preventing functional impairments. The option of building a more inclusive society is currently excluded from public-health cost-effectiveness studies.

An alternative measure developed before DALYs, which sidesteps the whole issue of subjective valuation of the effect of a disability, is disability-free life expectancy or, conversely, years spent living with a disability.¹⁶ Although recording the presence of a disability, this statistic does not apply any disability weights and thus does not entail any relative rankings on living with any particular disability.

Unfortunately, the advantage of sidestepping subjective valuation of disability is coupled with the disadvantage of being a very rough measure. The fact that all disabilities—irrespective of type or severity—are treated equally restricts this indicator's ability to rank various interventions. Clearly, whatever their valuation, all disabilities are not equal. Therefore, if this measure is to be used one must be very clear about what functional limitations constitute a disability. In essence though, this issue brings us back to the difficulty of disability weights and how one values quality of life.

Another criticism of DALYs is that they devalue the lives of women because they do not account for differences in social roles and how lives are lived. For example, infertility or facial scarring might have a greater effect on the life of a woman compared with a man, but generally disability weights used in the DALYs are the same for both sexes. Moreover, some critics are concerned that the expert panel that established this system of weights was probably dominated by men.¹⁷ How (they ask) can male experts be expected to assess the desirability of living with a disorder as a woman, especially if that condition—such as obstetric fistula or fibromyalgia—can only be experienced by women?

One of the biggest fears of critics of DALYs is that cost-effectiveness studies and cost-benefit analyses using this measure will drive resources away from people with disabilities. If extending the life of an individual with a disability only recovers a fraction of DALYs saved by extending the life of an able-bodied person then resources will flow to people without disabilities.

In truth, this scenario is not how DALYs are intended to be used. By assessing an intervention, the burden of disease is measured in such a way that a life lost (or the onset of a condition that leads to a disability) has the same effect irrespective of who is affected. That is, a year of life saved is equal to 1 DALY irrespective of whose life it is. An illness with a disability weight of 0·8 represents a loss of 0·8 DALYs even if it is contracted by an individual who already has a condition with an associated disability weight.

Critics argue that this method might be the way in which DALYs are used in cost-benefit analysis of a particular intervention, but when assessing summary measures of public health, saving the lives of people without disabilities still has better value for money. As Erik Nord states: "The point is simply that weights that are meant to encapsulate trade-offs by definition do not encapsulate the principle of protecting the lives of the disabled and the non-disabled equally strongly. They do not do so because they are not meant to do so, and that is precisely the ethical problem."¹⁸

Furthermore, if an intervention will enhance the lives of people with disabilities without eliminating their underlying medical disorder (if indeed such a condition exists, since not all functional states, impairments, or disabilities arise from a particular illness), absolutely no measured benefit is gained. Thus, relying on DALYs will drive public-health resources away from people with disabilities. Again, this situation is because health is viewed as a medical disorder and not as people's capacity to live full lives irrespective of their functional status.

Another challenge to DALYs with respect to cost-benefit analysis is that they "fail to give priority to those who are worst off (eg, on the basis of ill health or low social class); [and] they discriminate against people with limited treatment potential".¹⁹ In fact, this opinion is in opposition to the oft-expressed societal preferences of prioritising assistance to the most disadvantaged individuals. The way DALYs work now, claim critics, the neediest people will receive the least.³ In effect, analysis based on DALYs is utilitarian in its purest sense.

There are three main responses to this line of reasoning. First, as stated above, the methodology for cost-benefit analyses weights the lives of all people equally since irrelevant disabilities are ignored when calculating the effect of an intervention. Second, DALYs benefit people with disabilities by raising their profile. Finally, this measure represents a consistent and

quantifiable basis on which to make decisions that would otherwise be left to the interplay of advocacy groups and not be based on epidemiological principles.

In the end, however, use of DALYs is difficult for two major reasons. First, they preclude the consideration that public resources could also be used to better the lives of people with disabilities. Second, the way disability is defined is not consistent with that of the disability-research community, the ICF, or organisations for people with disabilities. Even if one is only considering prevention and not rehabilitation or mitigation, the fact still remains that disability, as encapsulated by DALYs, is divorced from the experience of living in a particular society while possessing differing functional limitations. This point goes back to the previous discussion on what is meant by disability and health. This inconsistency, as argued before, undermines the effectiveness of DALYs as an outcome measure for policies and programmes aimed at prevention.

By incorporating disability into its construction, DALYs rightfully raise awareness that differences in functional limitations—and not just mortality—should be incorporated into assessments of population health and interventions designed to enhance public health. However, the notion of health and disability embedded in this measure raises strong concerns.

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.

Even if one accepts the social model of disability, are DALYs well suited to assessment of interventions aimed at prevention? Prevention of disabilities is an important goal, but there are two key types: (1) prevention of medical conditions that lead to body function or structure limitations; and (2) prevention of the social and environmental conditions that stop people with those types of limitations from being able to participate in social and economic activities. DALYs address body structure and function tasks but not participation and activities. However, even considering the first type, which is very important, DALYs fall short because of how disorders are quantified. In particular, they are assigned a weight based on the desirability of a functional status in a particular social and economic environment, using central tendencies that do not incorporate the reality of living life with a disability as experienced by disabled people themselves.

Some people might also argue that DALYs give credit for interventions that cure health conditions leading to disability. There are several points to make here. First, this argument relates back to the medical model of disability that focuses solely on individual functioning. Still, a medical intervention can remove a functional limitation that is at the root of an individual's disability. As such, DALYs would pick up this improvement in people's lives, although to the exclusion of strategies that might accommodate different types of functioning, which could possibly be more cost effective—a key point of this Viewpoint. 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). Further, a focus on a medical cure instead of a holistic approach to health care, rehabilitation, and accommodation, which is where use of DALYs tends to lead, is inherently limiting. Finally, many disorders related to disability—cognitive limitations, amputations, blindness, reduced functioning from old age, etc—cannot be eliminated.

In the end, the main difficulty with DALYs is that they do not value interventions that enhance the lives of people with disabilities. To do so, they must draw on the social model of disability to look at how the environment interacts with functional status.

Disability is complex and multifaceted, with its roots in culture. Collapsing it into one indicator that must be additive to a measure of longevity is difficult. A better approach would be to rethink what measures are needed for different objectives and how to best calculate them. We should develop a limited set of measures aimed at addressing different aspects of health, which coincide within the approach taken by the ICF. Health—and indeed disability—is too complex to be encapsulated with one measure.

Conflict of interest statement

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