

# **DISABILITY, EPISTEMIC HARMS, AND THE QUALITY ADJUSTED LIFE YEAR**

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## **Abstract**

Health economists use a conceptual tool called the QALY in resource allocation decisions. Despite claims that the values of disabled people are distorted by adaptive preference, I argue that their testimony is in fact more reliable than that of non-disabled third parties. Epistemic injustice in this context harms disabled people and people with chronic illnesses. It also prevents us from challenging the current hegemonic and ableist formulation of the problem of just resource allocation. Community-based participatory research that gives disabled people greater agency in the research process would allow the reframing of the research problem.

**Keywords:** quality adjusted life year, epistemic injustice, transformative experience, standpoint theory, community-based participatory research

## **1. Introduction**

Health policy makers use utility measures to inform resource allocation decisions. They often rely on a conceptual tool called the quality adjusted life year, or QALY, that discounts the value of years lived in a state of disability relative to years lived in full health. A representative sample of the general public is asked to place values on hypothetical health states as part of a standard

gamble or time trade off task. Policy makers use the resulting values to calculate the number of QALYs gained through particular interventions. Utilitarian reasoning mandates that policy makers maximize QALYs gained per unit cost.

While many scholars have explored the problems of distributive justice that arise from this system of priority setting, the problem of epistemic harms to disabled people and people with chronic illnesses remains largely unexplored (Brock 1995; Singer et al. 1995; Nord et al. 1999; Bogner 2010; Sinclair 2012; Li 2015; Campbell and Stramondo 2017). Why are policy makers largely neglecting the testimony of disabled people and people with chronic illnesses in favor of that of the general public, when people without disabilities (who primarily make up this group) are less knowledgeable about the health states in question than those who have actually experienced them?

Policy makers justify their decision to solicit values from the general public rather than specifically from disabled people or people with chronic illnesses in a number of ways. Some appeal to the insurance principle, whereby decisions about what benefits will be covered must be made prior to the onset of illness or disability. Others argue that as the resources to be allocated belong to the general public, their values and priorities should be given due weight (Dolan 1999).

Finally, many argue that the testimony of disabled people or people with chronic illnesses is unreliable. Typically, this charge is directed toward disability positive testimony—testimony that disabled people value their disability experiences, or that they even prefer being disabled to being non-disabled. For those born with disabilities, the concern is that they value disabled states simply because they don't know any better (Scully 2018). For persons who have acquired disabilities later in life, the concern is that their values and testimony are irrationally biased by adaptive preference (Dolan 1996 and 1999; Nussbaum 2001; Brock 1995 and 2005).

I argue in what follows that the current system of value solicitation for the QALY is epistemically unjust (Fricker 2007; Carel & Kidd 2014; Scully 2018). Not only are concerns about adaptive preference unfounded (Barnes 2009; Khader 2011), but disabled people and people with chronic illnesses are in fact in a better epistemic position to evaluate their own health states than people without disabilities (Paul 2014; Harding 1993). Their testimony is arguably more objective than that offered by the general public (Harding 1993; Amundson 2005). From an epistemic standpoint, policy makers should not be permitted to neglect their testimony by allowing it to be swamped by the values and preferences of people without disabilities.

One problem with mistakenly assuming a poor quality of life for disabled people and people with chronic illnesses is that it is easy to make the further assumption that these lives are somehow less valuable. Indeed, the QALY framework is built on the assumption that rational people will readily part with years of life with a disability in exchange for shorter lives in an able-bodied state. Making the voices of disabled and chronically ill individuals central to our inquiries has the power to demonstrate the ableist bias encoded in the QALY framework, a bias that unfortunately pervades medicine and society at large. That bias remains invisible while we neglect the testimony of disabled people and people with chronic illness.

## **2. A note on terminology**

While I refer to disabled people and people with chronic illness in tandem throughout this paper, I want to acknowledge that disability and chronic illness are not coextensive, and their boundaries are contested. Although many chronic illnesses are disabling, one can be chronically ill without being disabled—as may be the case when effective treatment eliminates daily

symptoms, and one can also be disabled and be perfectly healthy at the same time. Because many individuals with chronic illnesses do seek medical treatment, while the majority of disability rights activists fight medicalization of their conditions, the groups at times have different interests (Wendell 2001; Clare 2017). Yet both groups benefit from greater inclusion and structural justice; and, while individuals with different types of disability may require different supports and encounter different obstacles, all can benefit from political unity. The QALY addresses a wide range of conditions from both categories, disability and chronic illness, and the set of people I wish to refer to in this paper includes those whose conditions are evaluated by this tool.

Preferred terminology for referring to members of the disability community is contested. While most scholars in health policy prefer “people with disabilities”, feminist philosophers and philosophers of disability tend to prefer “disabled people”. Among members of the disability community, there has been a shift away from person first language (people with disabilities) toward identity first language (disabled people) in recent years; however, individual preferences vary. While this paper does address policy issues, I identify as a feminist philosopher of disability rather than a policy scholar and have chosen my language accordingly.

### **3. Background**

When researchers and policy makers are trying to determine the number of QALYs gained through a particular intervention, they ask a representative sample of the general public time trade off questions about hypothetical health states. Given the choice between, say, eight years with perfect function and ten years in a wheelchair, which option would they choose? Adjust the

numbers until the average person is indifferent between the two options, then divide to determine the number of QALYs—0.8 for example—the disabled state is supposedly worth. A year with full, healthy function is, by definition, valued at one QALY, and a state of health equal to death is valued at zero QALYs. The assumption is that the average person will value life in a disabled state less than life with full function, and that their choices in the time trade off task will reflect their preferences.

For a variety of reasons, researchers and policy makers who measure QALYs do not target disabled people or people with chronic illnesses when they solicit preferences for a given health state. Yet the practice of querying the general public is controversial since arguably non-disabled individuals who make up the majority of this population are epistemically ill-equipped to place informed values on chronically ill or disabled health states. They do not have detailed knowledge of the conditions they are evaluating or know what those conditions are like to live with day in and day out. Most valuations are based on gut reactions, and those gut reactions can be colored by bias (Hausman 2016). People without disabilities tend to systematically undervalue the quality of life of disabled people and people with chronic illnesses compared with these individuals' own valuations (Bagenstos and Schlanger 2007; Carel 2014).

Yet researchers and policy makers worry that soliciting values preferentially from disabled people or people with chronic illnesses may also be epistemically problematic. Jackie Leach Scully (2018) describes the common, though she believes mistaken, attitude that disabled people value their disability experiences only because they have never experienced the alternative. If persons born with disabilities were to experience life in a fully able-bodied state, they would surely prefer it and downgrade their valuations of disability (Singer et al. 1995). Sara Goering (2008) writes, "The charge is that a disabled person who reports a high quality of life

can only do so by denying the inherent constraints on her opportunity” (128). Peter Singer (2001) theorizes that if disabled people could take a magic pill that would erase their impairments, they would surely do so.

Similarly, some scholars are concerned about bias arising from adaptive preference. John Elster (1983) argues that agents sometimes demonstrate an irrational preference for certain states, as well as a downgrading of unattainable states, when faced with a restricted set of options. The classic example is the fox who claims that the grapes he cannot reach are too sour for foxes anyway. Elster distinguishes adaptive preference from preference planning, noting that adaptive preferences are non-autonomous. We do not arrive at them by choice, but are unconsciously forced to take them on in order to cope with frustrating limitations. On the other hand, preference planning involves an autonomous choice to cultivate new values and preferences—perhaps for a new food or a new hobby. The charge is that because values and preferences for disabled states are non-autonomous, they are irrational, and should therefore be discounted as unreliable. We do not choose to be disabled, but must find ways of mentally and emotionally coping with the condition once we find ourselves in it.

Martha Nussbaum describes a normative version of adaptive preference. Here the problem isn't a lack of autonomy, but the fact that agents come to value or prefer a suboptimal state. Consider a kidnapping victim who develops Stockholm Syndrome, and comes to prefer captivity, or a woman raised in an oppressively patriarchal culture who prefers that life despite the lack of opportunity for education, career, or reproductive freedom (Nussbaum 2001b). In each of these cases, the agent has come to value or prefer a state that is suboptimal—a state that is not consistent with a flourishing life.

According to Nussbaum's capabilities model of well-being, there are certain near universal, objective criteria that make a life worthy of human dignity. Among those are a full life-span, bodily health, the ability to move about in an unrestricted way, and the capacity to use one's mind and senses. We must have the freedom to experience these capabilities if we are to truly thrive as human beings. Unfortunately, these criteria seem to speak against the testimony of disabled people who claim that their quality of life is on a par with that of their non-disabled counterparts. Nussbaum believes that disabled people tend to exhibit adaptive preference—a preference for a suboptimal and unjust status quo imposed either by their impairment itself or by an unjust lack of accommodation. As a result, she discounts testimony from disabled people that life with a disability, or at least life without the capabilities she lists, can be compatible with true flourishing (Nussbaum 2001a).

#### **4. Epistemic injustice**

I argue that discounting the credibility of disabled people and people with chronic illnesses in favor of the judgments of people without disabilities is epistemically unjust. According to Miranda Fricker (2007), epistemic injustice is “a wrong done to someone specifically in their capacity as a knower” (1). One form of epistemic injustice is testimonial injustice. This injustice occurs when an individual's credibility is systematically underestimated due to social identity prejudice—that is, prejudice based on the social group to which a person belongs.

Fricker illustrates testimonial injustice by examining the plight of Tom Robinson from Harper Lee's (2015) classic novel, *To Kill a Mockingbird*. Tom, a black man living in 1930s Alabama, is falsely accused of rape by a young white woman and her father. His courtroom

testimony is systematically discounted by the all-white jury considering his case, despite the other evidence supporting his account. Fricker's explanation for the jury's verdict is that, given the racist prejudices of the day, they see black men as untrustworthy sources of testimony.

Fricker also describes a second form of epistemic injustice—hermeneutic injustice. Hermeneutic injustice occurs when dominant groups control the interpretive resources available to describe experience, and, as a result, there is a lacuna in the conceptual resources needed to understand and communicate the experiences of a marginalized group. For instance, without the concept of sexual harassment, women were prevented from understanding unwanted sexual advances in the workplace as a structural injustice (Fricker 2007). Instead, they were pushed to conceptualize these advances as harmless flirting, all in good fun, or as boys-will-be-boys behavior.

While Fricker (2007) focuses on marginalized groups such as women and persons of color, Carel and Kidd (2014) and Kidd and Carel (2017) extend the discussion to include patients. Carel and Kidd argue that patients are vulnerable to epistemic injustice, since medical professionals and policy makers often underestimate their competence as informants. Patients are, for instance, said to be overly emotional (and hence irrational) and prone to include irrelevant and unhelpful information in their accounts of their experiences with illness (Carel and Kidd 2014; Kidd and Carel 2017). Scientifically objective, clinical accounts of illness given by medical professionals are epistemically privileged over the more phenomenological accounts rendered by patients.

Alison Reiheld describes a number of examples of testimonial injustice in healthcare in her 2017 lecture, "I Can Hardly Credit It: Epistemic Injustice in the Patient-Provider Relationship". For instance, Reiheld describes a race and gender gap in the prescription of pain

relief for patients. Women tend to be viewed as incompetent reporters, and their pain is frequently discounted as psychiatric in origin, while African Americans tend to be viewed as insincere and potentially drug seeking. Fat patients are often viewed as difficult or non-compliant, and their testimony about physiological symptoms is often dismissed. Many doctors are unwilling to consider non obesity-related causes for illness or disability.

Jackie Leach Scully (2018) argues that disabled people are also frequently subject to epistemic injustice. For instance, their testimony about the inadequacy of accommodations is often discounted as incompetent, and complaints about ableism are dismissed as overly sensitive. Both Scully (2018) and S. Kay Toombs (1995) observe that disabled people are often treated as globally incompetent, even when they only experience a single form of disability. For instance, Toombs, who has multiple sclerosis, notes that when she uses her wheelchair, basic questions about her preferences are frequently directed not at her, but at her husband. Years ago, I spent two months in a wheelchair following a serious car accident, and several members of my department congratulated me on being able to complete my qualifying exam in such a state—as if I had injured my head rather than simply my leg and ankle.

Fricker's account conceives of epistemic injustice in terms of a credibility deficit. However, Jose Medina (2013) argues that epistemic injustice can also take the form of credibility excess. Our assessments of credibility are comparative and proportional, and an excess granted to a socially privileged group often goes hand in hand with a deficit in credibility for a more marginalized group. While we normally think of medical professionals as rightly deserving credibility excess, and in many contexts high credibility is appropriate, in the context of quality of life assessment, that excess is unwarranted. Similarly, we see that the health state valuations of people without disabilities are given an unjust excess of credibility as compared to the

evaluations of disabled people. Credibility excess afforded to privileged groups harms not only people who are not afforded such privileged status, but also erodes the epistemic virtues of its recipients. When our valuations and opinions are consistently granted high credibility, we may become arrogant and lazy, and lose the motivation to seek out contrary understandings.

Finally, Elizabeth Barnes (2016) describes the hermeneutic injustice facing members of the disability community. The able-bodied tend to control society's hermeneutic resources surrounding the experience of disability, leaving disabled people hermeneutically marginalized. The medical model dominates both among the general public and among health professionals. Thus, disability tends to be interpreted as a personal tragedy rather than a structural injustice, and the source of disability is located in the individual rather than in the social environment. For instance, members of the Deaf community reconceptualize themselves as a linguistic and cultural minority, rather than seeing themselves, as others typically do, as impaired individuals needing medical intervention. Greater public literacy in ASL or other sign languages would alleviate obstacles in communication between the Deaf community and the general public (Kafer 2013, 74-76).

The disability rights movement has worked to address the hermeneutical lacuna that prevents disabled people from understanding themselves and communicating to other people that they are able to thrive not just in spite of, but often because of disability. It has worked to make room for disability pride (Barnes 2016). The movement has also worked to reconceptualize disability in ways that facilitate social justice and greater civil rights for the disability community. By rejecting the dominant medical model of disability, disabled people are able to point to social and structural barriers in the workplace, in education, in transportation, and in the healthcare system that make it more difficult for them to flourish. They are more able to demand

social and political change, and to challenge the idea that the seat of the “problem” is in themselves.

A parallel way of conceiving of the problem of hermeneutic injustice is to look to restrictive formulations of the social imaginary. Powerful social and cultural scripts determine what relations or states of affairs we find either incredible or easily imaginable. The dominant social script surrounding disability is one of tragedy and misfortune, and that makes it difficult for people without disabilities to imagine disabled people thriving and happy. Where we do find thriving, it must be because the subject has struggled to overcome his or her disability in inspirational fashion.

Our social scripts tell us disabled people are both dependent and incompetent, and this makes it difficult for us to imagine them living independently, being valuable members of the workforce, or effectively parenting their own children. If we are to pursue epistemic and social justice for disabled people and people with chronic illnesses—including the right to live and work in the community, and the right to build their own families—we must work to expand our social imaginary and to write new social and cultural scripts surrounding the experience of disability. We must also engage with disabled people as knowers and give the hermeneutic resources they develop to explain their own experiences proper uptake (Pohlhaus Jr. 2012). Failing to do so constitutes what Gaile Pohlhaus Jr. calls willful hermeneutic ignorance.

## **5. Comparative ignorance and adaptive preference**

I suggest that an example of epistemic injustice toward disabled people and people with chronic illnesses is the assumption on the part of policy makers and researchers that their valuations of

health states are not credible, either because they have not experienced non-disabled states, or because they tend to adapt to limiting conditions.

First, we often accept testimony about the values and preferences of able-bodied persons, even when they have incomplete information with which to make comparative judgments. The fact that I value or even prefer being a philosopher to being a musician, or an EMT, does not seem strange (well, maybe it does) to my peers, despite the fact that I have not tried either of these alternative professions. They do not find me insincere or question my competence as an informant. Women are not presumed to be incompetent to value their lives qua women, even if they haven't experienced life as a man. Yet disabled people are presumed to be incompetent when they place high values on their disability experiences or indicate a preference for their current health state. (See Barnes 2016 for a similar argument.)

Martha Nussbaum (2001a) and Dan Brock (1995; 2005) have argued that disability positive testimony, that is testimony from disabled persons that they value or even prefer being disabled to being able-bodied, is evidence of adaptive preference, since, clearly, disabled states are suboptimal. Bioethicist Dan Brock (2005) compares persons who value or prefer living with a disability to “happy slaves”. Disability positive testimony is discounted by researchers and policy makers as irrational, and problems of adaptive preference are offered as justification for seeking the health state valuations grounding the QALY from the largely able-bodied public rather than disabled people and people with chronic illnesses.

Contrary to Nussbaum and Brock, Barnes (2009) argues, that, *ceteris paribus*, we should view individuals' assessments of their own well-being as more accurate than those of arbitrary third parties. Barnes (2009) further notes that we cannot use the popular assumption that disability is suboptimal—and therefore subject to adaptive preference—to epistemically

undermine disabled persons' positive assessments of their own well-being, since the fact that disability is suboptimal is exactly what is in question. While there may be instances in which the testimony of disabled people or people with chronic illnesses is less than credible, a systematic prejudice against accepting their testimony is epistemically unwarranted.

Similarly, Serene Khader (2011) warns against assuming that persons whose preferences are different from our own must be exhibiting adaptive preference. Like Nussbaum, she holds a normative view of adaptive preference, but she also observes that difference is not to be confused with detriment. Persons who exhibit a preference for Deaf culture over hearing culture are a paradigm example. We are often oblivious to value trade-offs made by those differently situated from ourselves, seeing only what is lost and missing what is gained. It is perfectly plausible that many individuals who prefer life with a disability gain something through their conditions that more than makes up for perceived losses.

## **6. Chronic illness and disability as transformative experience**

In this section, I extend Barnes's (2009) assertion that the testimony of disabled people and people with chronic illnesses regarding their own well-being is more credible than that of arbitrary third parties by arguing, following L.A. Paul (2014), that becoming disabled or chronically ill is an epistemically and personally transformative experience. Paul (2014) notes that, "People with different skin colors, genders, or histories will have very different experiences in their day-to-day interactions. If you are a man who has grown up and has always lived in a rich Western country, you cannot know what it is like to be a woman living in Ethiopia, and if she has never left her village, she cannot know what it is like to be a man like you" (7). I argue

that the same is true of the experience of living with a disability or chronic illness. Indeed, Paul (2014) admits as much in her book, particularly in her discussion of hearing vs. deaf parents and the decision each party must make about whether to pursue cochlear implant surgery for their deaf children (56-70). Barnes (2016) also references Paul's work on transformative experience in her recent book, *The Minority Body*, claiming that becoming disabled is a transformative experience (107).

An epistemically transformative experience is a subjective experience that we cannot imaginatively project ourselves into prior to living through it. Because we cannot imagine what a transformative experience will be like, we cannot make rational decisions regarding its relative value or desirability. For instance, a hearing individual cannot accurately envision the subjective experience of life as a member of the deaf community or rationally decide to become deaf by imaginatively projecting himself into that state in order to ascertain its value. Nor can a person born deaf accurately assess, at least through projective imagination, the value of acquiring a foreign fifth sense, according to Paul (2014).

Often, experiences that are epistemically transformative are also personally transformative, which compounds difficulties in assigning values to undergoing those transformations. A personally transformative experience alters our values and preferences in ways that may be unpredictable (Paul 2014). At best, we may be able to guess what our new preferences might be by asking those who have already undergone the transformation in question. Research on response shift in quality of life measurement shows that individuals who become chronically ill or disabled adapt to their conditions over time in ways that change their values and preferences (Schwartz and Sprangers 1999). Persons with recently acquired chronic

illnesses and disabilities reconceptualize what it means to be limited and what it means to be doing well, and they reprioritize their values in response to their new lives.

Because, on the view I have been discussing, acquiring a chronic illness or disability is an epistemically and personally transformative experience, healthy and able-bodied individuals cannot accurately project themselves into the subjective experience of disabled people or people with chronic illnesses and thereby assign values to their health states. And yet, this is exactly what quality of life researchers and policy makers ask of healthy and able-bodied individuals when soliciting valuations for QALYs. Researchers describe hypothetical health states in a few sentences, ask respondents to imagine life in those states, and then confront them with time trade off or standard gamble tasks involving those health states. They ask them to make a choice about a state they are ignorant about, and to compare its worth to their present state. But if becoming disabled or chronically ill is epistemically and personally transformative, individuals cannot reliably complete these tasks for hypothetical health states that they have never experienced. For this reason, I argue that the healthy and able-bodied are, at least by themselves, epistemically ill-equipped to make judgments about the quality of life of disabled and chronically ill individuals (i.e., to place values on those health states) in the ways that researchers ask them to.

## **7. Standpoint epistemology**

Standpoint epistemology also supports the idea that disabled people and people with chronic illnesses are in a better position to evaluate their own well-being than third parties, particularly when those third parties are able-bodied. Standpoint epistemology argues that all knowledge is situated—what we are in a position to know depends on our social location. Furthermore,

marginalized groups, in at least some contexts, occupy epistemically advantaged positions relative to their socially dominant counterparts. For instance, black Americans are aware of structural problems of racial prejudice and discrimination that white Americans are largely unaware of because these social obstacles do not similarly affect their lives. The same is true of disabled individuals, whose knowledge of social and structural barriers to accessibility and inclusion is greater than that of the able-bodied public. W.E.B. Du Bois (1903/1996) described the double consciousness that members of marginalized groups tend to develop. Not only must they be cognizant of dominant social understandings and ways of getting along in the world, they are also aware of subversive systems of social knowledge.

While some may claim that third person testimony—particularly the testimony of clinicians—about quality of life is more objective than first person testimony (see for instance Brock 1995 and 2005), Amundson (2005) warns that third person perspectives are often colored by prejudice or stigma surrounding disability. For instance, third parties may assign low values to disabled states because of the prejudice that living with a disability is inherently a misfortune and is worthy of pity. Rather than replacing subjective assessments by disabled people with objective assessments of quality of life by the healthy and/or able-bodied, Amundson (2005) suspects that we are simply replacing one subjective assessment with another.

Feminist scholar Sandra Harding (1993) suggests that knowledge built from the perspective of marginalized lives can in fact be more objective—that is, less biased and distorted—than knowledge built from a dominant perspective. In this case, working from the perspective of disabled people, and engaging with their lived experience, would generate less biased or distorted research problems and hypotheses. Harding calls the objectivity we achieve by taking this standpoint “strong objectivity” to emphasize that rather than taking a single,

dominant perspective for granted (usually a white, male, straight, able-bodied perspective), those who explore the world from the perspective of the marginalized instead exhibit greater transparency of social and cognitive values.

Finally, the epistemic privilege discussed by standpoint theorists is neither automatic or essentialist. We are not born into a standpoint but must cultivate one through reflection and political engagement. Harding (1993) emphasizes that this standpoint will not be monolithic but, as it is a feature of communities rather than individuals, will encompass heterogeneous and sometimes even contradictory points of view. Intersectionality matters. The knowledge and perspective of an older woman with multiple sclerosis will be very different from the knowledge and perspective of a young man with an intellectual disability. The experience of a person of color with mental illness will be different still. We should use the heterogeneity of perspectives we encounter within any marginalized group as a resource for discovery.

## **8. Epistemic harms and social harms**

In what sense is the effective epistemic exclusion of disabled people and people with chronic illness in the valuation of health states a harm to these groups? Other scholars have discussed the potential for distributive injustice arising out of current practices of soliciting values primarily from the healthy and able-bodied (Brock 1995; Singer, McKie et al. 1995; Nord et al 1999; Bogner 2010; Sinclair 2012; Li 2015; Campbell and Stramondo 2017). My focus here will be on epistemic and social harms associated with exclusion.

According to Fricker (2007), being a valued informant, or a rational knower, is essential to being fully human. Human beings are defined by Aristotle (1984) as rational animals, and for

Kant (2012), our rationality is the seat of our value in the human kingdom of ends. It is what makes us both morally considerable, and qualified moral agents. To denigrate a group's status as rational beings, or as valued informants, is to render them outcast. The current practice of effectively epistemically excluding disabled people and people with chronic illnesses from the process of health state valuation denies the moral agency of these groups by failing to hear and respect their values and preferences. Part of what it means to be an autonomous moral agent is to have values and priorities, and for those values and priorities to be recognized and respected by others.

Both Ann Cahill (2014) and Gaile Pohlhaus Jr. (2014) talk about the epistemic and ethical process of "othering", or "derivatization". When certain subjects are rendered other in our interactions, experiences that differ from those of the dominant group are suppressed or even treated as treasonous. Rather than being fully recognized as epistemic agents, those labeled other are valued only insofar as they can reinforce the epistemic experiences of the dominant group. Their role in the intersubjective pursuit of knowledge is truncated. Being a trusted informant and bona fide subject is an essential part of being a contributing and valued member of a community. Systematically trusting or dismissing a person or group's testimony, or their way of conceptualizing their experience of the world, is a way to facilitate or deny their full participation in society.

Seeking out the testimony of a person or group is a way of conferring status or recognition. Disabled people and people with chronic illnesses are often denied full participation in the workplace, in education, and in social and recreational spaces. A central goal of the disability rights movement is to secure full participation and inclusion in the community for

disabled people. This participation should extend to epistemic inclusion and recognition of the status of the disability community as valuable informants.

Other harms associated with excluding the voices of disabled people and people with chronic illness in favor of healthy or able-bodied voices include the perpetuation of the “personal misfortune” model of disability and the marginalization of the social model of disability. Ableist bias leads most healthy and able-bodied individuals to view the “problem” of disability as seated in the individual. Many disability advocates instead espouse a social model that locates the problem not solely or even primarily with the individual’s impairment, but with the failure of society to adequately accommodate diverse (and no less valid) ways of being in the world. Conceiving of disability as a personal misfortune rather than a social justice issue removes the impetus to pursue structural changes that would make a positive difference in the lives of disabled people.

Many, though certainly not all, disabled people see their conditions not as a misfortune, but instead as valuable sources of diversity. On average, disabled people rate their quality of life only slightly lower than do able-bodied individuals, and significantly higher than do third party proxies such as spouses, caregivers, or health care professionals (Ubel et al. 2003; Bagenstos and Schlanger 2007; Carel 2014; Campbell and Stramondo 2017; Scully 2018). A 1997 study by Paul Dolan, for instance, reported that healthy interviewees using the EuroQOL utility measure rated over 80 disabled states as worse than death while persons living with those same conditions reported near normal levels of quality of life (Carel 2014). One problem with mistakenly assuming a poor quality of life for disabled people and people with chronic illnesses is that it is easy to make the further assumption that these lives are somehow less valuable. Indeed, the

QALY framework is built on the assumption that rational people will readily part with years of life with a disability in exchange for shorter lives in an able-bodied state.

The way policy makers and researchers frame their questions—how many years of life with a disability would you give up if it meant you could regain full function?—constrains the sorts of responses that are expected and considered acceptable. Social science research shows that framing effects can have a powerful impact on survey responses (Dillman et al. 2014). The way we pose our questions matters. This particular frame reinforces the tendency to see disability as a misfortune, and places disability positive testimony outside the social imaginary.

Yet even under this frame, when disabled people are presented with time tradeoff tasks, evidence shows they are unwilling to part with more than a negligible period of life with a disability given the opportunity to trade (O’Leary et al. 1995; Fowler et al. 1995). The assumption we are encouraged to make, that disabled life years are worth less than able-bodied years, may seem obvious to an able-bodied person, but for disabled people or people with chronic illnesses, the suggestion is problematic. This is because disabled people and people with chronic illnesses have often been pushed by their experiences to develop hermeneutic resources the general public either does not have access to or chooses to ignore (see Pohlhaus 2012). Over time they find positive ways to interpret their disability experiences. They come to find value in disability and even chronic illness.

Thus, by failing to actively solicit the voices and values of disabled people and people with chronic illnesses, we also fail to question a hegemonic decision-making framework—a framework that has important implications for the well-being of those same people. We fail to give proper uptake to the hermeneutic resources developed by this marginalized group, and so choose to remain ignorant about their lives. We choose to remain ignorant about the quality of

their lives and the ways access, or lack of access, to healthcare affects them. Is there a way to challenge this hegemonic framework and still address the problem of resource allocation in health care?

## **9. Indispensable informants, participatory research**

If health economists wish for their research to be both epistemically just and epistemically sound, they must treat disabled people and people with chronic illnesses as indispensable informants. Failing to do so harms members of these communities, both epistemically and socially, and perpetuates a hegemonic utility based decision-making framework. To remedy these harms, the values and perspectives of disabled people and people with chronic illness must be placed at the center of inquiries about just resource allocation, and the disability community must be given the opportunity to reframe the questions being asked.

It might seem that merely increasing the representation of disabled people and people with chronic illnesses among respondents would be sufficient to address the epistemic and social harms I have discussed. However, this would not address the ableist bias built into the QALY framework—the assumption that respondents will naturally value disabled years less than able-bodied years and will thus be willing to sacrifice a significant portion of life in a disabled state for the opportunity to be able-bodied. It will not challenge health economists’ assumptions that disability is a personal misfortune rather than a social justice issue. These assumptions restrict the interpretive and testimonial freedom of the disability community to voice their values, preferences, and priorities, and it delimits their input into resource allocation decisions.

Marginalized stakeholders, such as disabled people and people with chronic illnesses, often complain that researchers fail to address the problems that truly affect their community, and that outcomes fail to translate into positive social change for their group. They sometimes feel that scientists are more interested in furthering their own research agendas than in confronting the issues that affect the daily lives of marginalized subjects. Research results may not be translated into accessible formats that might be effectively used by stakeholders. Marginalized communities may feel taken advantage of—they may bear the burdens of research without reaping the rewards (Jordan et al. 2015).

In part, this lack of trust comes from the mismatch between the types of research problems social scientists feel capable of addressing—clean and circumscribed—and the much messier problems community members face. Distrust also arises because social scientists are taught to remain detached from their research subjects. The social and epistemic norms social scientists follow do not translate well outside the scientific community. Open communication is key to establishing trust and good working relationships between scientists and community members (Jordan et al. 2015).

Philosophical literature on community-based participatory research suggests that researchers should act as facilitators, sharing agency and power with stakeholders and local experts (Jordan et al. 2015). When conducting research with marginalized stakeholders, those stakeholders should be empowered to help shape the research agenda and the ways research questions and hypotheses are formulated. Stakeholders often have valuable expertise to share with researchers, despite their lack of formal credentials. They can help challenge researchers' preconceptions and biases and offer valuable alternative interpretations of research data (Jordan et al. 2015).

Stakeholders and local experts should also help determine the shape and extent of their own participation. In addition to participating in focus groups or interviews as subjects, locals may also choose to partner with researchers, acting as intermediaries between scientists and the larger community, for instance, as interviewers or community educators. They may have more credibility in these roles than outsiders, and thus be in a position to gather better data than researchers themselves. They may take part in knowledge translation and dissemination activities once research is completed in order to more effectively share results with their communities (Jordan et al. 2015).

If health economists and policy makers are willing to conduct community-based participatory research, they will give disabled people and people with chronic illnesses the opportunity to take part in framing the problem of just resource allocation and its relation, if any, to health utility. Making conceptualization of the research problem a joint venture is one way to address the ableist bias currently distorting the QALY measure. Certainly employing a time trade off task to solicit preferences is problematic. Yet, even with more accurate values for disabled health states supplied by the relevant communities, it may not ultimately make sense for health resource allocation decisions to rest on the utilities of health outcomes. Whether they should is not a question I will attempt to address here, as I believe it is best addressed by the community as a whole, in a way that takes seriously the voices of disabled and chronically ill persons.

While I do not deny that the healthy and able-bodied should also have a role in framing the problem of just resource allocation, I am acutely aware that democratic processes of deliberation tend to uphold existing power relations and to privilege the viewpoints of those who hold socially dominant positions (Young 2001). Merely increasing the representation of disabled people and people with chronic illnesses will not solve this problem if deliberators do not seek

out input from these group members and take their voices and viewpoints seriously. Participants who occupy positions of privilege must exercise the virtues of epistemic humility, curiosity, and open-mindedness if the voices of disabled people and people with chronic illness are to be given a just hearing (Medina 2013). By pursuing epistemic justice toward these groups, we take an important step toward making our communities more inclusive.

## **10. Conclusion**

Health economists and policy makers use utility measures and a conceptual tool called the QALY to aid in health resource allocation decisions. I have argued that epistemic justice requires us to place disabled people and people with chronic illnesses at the center of our inquiries about health state values and resource allocation. While some claim that the values and preferences of disabled people are distorted by adaptive preference, I argue that their testimony is in fact more objective and more reliable than that of third parties. Epistemic injustice in this context harms disabled people and people with chronic illnesses by perpetuating the “personal misfortune” model of disability and marginalizing the social model of disability. It also prevents us from challenging the hegemonic and ableist formulation of the problem of just resource allocation, as it is currently presented by health economists. Community-based participatory research that gives disabled people and people with chronic illnesses greater agency in the research process would allow the reframing of the research problem.

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