Our Lives and Ideologies

The Effect of Life Experience on the Perceived Morality of the Policy of Physician-Assisted Suicide

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The opposition to a public policy of physician-assisted suicide from within the disability-rights community seems to be surprising to academics who are supporters of other civil rights movements. Physician-assisted suicide is seen by them as a part of a progressive political agenda, akin to abortion rights and the civil rights of minorities. Many disability-rights advocates see physician-assisted suicide as quite the opposite—an example of discrimination against people with disabilities and a threat to their individual rights. The great conflict between these two interpretations is not much reduced by listening to one another's arguments. Perhaps it will be better understood by considering how the political beliefs of real individuals have been changed by their own experiences with disability. This article reports how two individuals were led to change their beliefs about physician-assisted suicide as a result of their life experiences with disability.

The authors of this article have known each other for 20 years. We met as a professor of philosophy and an undergraduate philosophy major. The professor is still a professor. The student graduated, raised a family, and is now preparing for graduate school. We live in the same city and have remained in contact over the years. Neither of us is particularly interested in ethical or social philosophy. The professor does research in the history and philosophy of science, and the pending graduate student is interested in epistemology and metaphysics. We share one interest in social philosophy: the issue of physician-assisted suicide. We agreed on the issue in the early 1980s, and we agree on the issue today; but we have both changed our minds between those two times.

This is not a philosophy paper, but a sort of combined intellectual autobiography. Our opinions about assisted suicide have changed because our lives have changed. We both now live with disabilities. In the 1980s we had political views to the left of center, and we still do. In those days we agreed with other liberals that legalized physician-assisted suicide should be a right provided to competent adults on the grounds of self-determination. We now believe that a social policy of assisted suicide would be a threat to the rights and to the lives of people with disabilities and other disadvantaged and stigmatized groups. We are still committed to self-determination as a basic human right. However, true self-determination must be based on genuine choices, not choices that are forced or coerced. We no longer believe that assisted suicide could be a genuine choice to people with disabilities and other stigmatized groups.

This special issue of the *Journal of Disability Policy Studies* is premised on the notion that disability-rights opponents of assisted suicide can find common ground with conscientious advocates of the policy. We (the authors) are not entirely convinced that this is true. The nondisabled mainstream of modern society is steeped in the notion that disability is something that happens only to others. Average people spend no more time thinking about their own future disability than they do thinking about suddenly changing into the other sex or into a different race. And so we suspect that our reports will simply be read for anthropological interest: "What life is like to the native." Nevertheless, statistics indicate that the majority of the nondisabled readers of this article will experience serious disability at some time in their lives. If you're lucky you will live a long time with that disability, rather than die from it. So you are us. Think of us as citizens of a county you may be moving to, rather than aliens from a world far, far away.

Ron's Story

I had polio in 1952 at the age of 6 years. The immediate effects were relatively minor, a weakened right leg and an oddly shaped foot. Like many polio survivors I was a "passer" for most of my life and didn't think of myself as disabled. Post-Polio Syndrome began to hit me in 1988. It affected me more than polio had, with weakening and chronic leg pain, and extreme exhaustion in the afternoons. In 1992 I began to use a wheelchair for mobility. This and other lifestyle changes help me to manage the effects of Post-Polio Syndrome. I plan my day carefully, with regular rest periods and very efficient use of travel time. My home and work environment are modified, both for wheelchair accessibility and for the reclining posture that allows me to work without pain. These changes have allowed me to continue to work as a full-time academic.

I am now very well accommodated to my impairments, but at first they were distressing, and it was hard to concentrate on my usual research. Around 1990 I decided to look into philosophical writings on disability. Because I was obsessed with my own increasing disability anyhow, I thought that I could concentrate better by using disability as a research topic. I was amazed to discover that practically no work had been done by philosophers on physical disability.

The Americans with Disabilities Act was passed in 1990. It was backed by a sophisticated civil rights campaign, and what can only be called a philosophical reconceptualization of the nature of disability itself. When I discovered this new philosophy of disability I was thrilled with its elegance. At the same time I was appalled at the ignorance of the academic philosophical community toward these ideas. The disability-rights movement had gotten the Americans with Disabilities Act through Congress, based on philosophical concepts of which the American Philosophical Association was unaware.

The basic tactic of the disability rights movement was to distinguish between the biomedical impairments of people with disabilities and the disadvantages that result from these conditions. Nondisabled society had always assumed that impairments were the direct cause of disadvantages. People with disabilities have a high risk of being unemployed, immobile, uneducated, and poor. This is usually thought to be because of their disabilities. The disability rights movement had a different causal story. The disadvantages of people with disabilities came not from their impairments but from the inaccessibility of the environment around them. Consider a wheelchair user who couldn't get an education because she couldn't get into her local school. This person was harmed not by her own biomedical condition, but by the design of the school. Impairments themselves do not cause unemployment and social isolation. These disadvantages are caused by social prejudice and by the environmental barriers that this prejudice caused to be built.

Our society used to worry about "the Race Problem" and "the Woman Problem." We now recognize that race and sex (the actual differences between races and between sexes) are not the cause of those problems. Destructive social attitudes are to blame. Racism and sexism are the names of the destructive attitudes. The disability-rights movement is based on identical reasoning. Bodily differences are not the causes of our problems, a destructive social prejudice is to blame; we call it ableism. Ableism is a doctrine that falsely treats impairments as inherently and naturally horrible and blames the impairments themselves for the problems experienced by the people who have them. Ableism is wrong. Disability is a social problem, not a medical problem. Impairments are not the problem; ableism is.

I report on this new concept of ideology not because I expect the reader to accept it. I know from experience that nondisabled people have a very hard time swallowing it (just like we all had a hard time recognizing our own racism and sexism). Nevertheless, when I replaced in my own mind the ideology of ableism with the ideology of the disability rights movement, it caused my conversion from an advocate to an opponent of physician-assisted suicide. That's why I am telling you about ableism.

Now I will explain how my rejection of ableism led to my rejection of physician-assisted suicide. It came from listening to the arguments made by assisted-suicide advocates in support of their positions. At the core of these arguments are a few classical cases of people with serious disabilities who wanted to commit suicide. The assisted-suicide advocates' use of these cases was blatantly ableist. They would describe the person's impairments, in the most demeaning possible terms, and then ask "Wouldn't you want to die if you were in that position?" Their ableism was obvious from the fact that they took the impairments themselves as the true reasons for the death wish. From my (new) perspective it was obvious that these people wanted to die because of their social situation, not because of their impairments. In one case, a quadriplegic man was being forced to live in a filthy, restrictive, and geographically remote institution. He was refused the support he needed to live independently near his friends and family. Wouldn't you want to die if you were institutionalized against your will and taken away from your family? Of course. But the assisted suicide advocates blithely assumed that his quadriplegia alone, not his social circumstances, caused his despair. Because his quadriplegia could not be cured, he should have the "right to die." It never crossed their minds that his death wish would vanish if he were given the support he needed to live freely among his friends, as all human beings want to do.

I began to notice that when assisted suicide advocates really wanted to scare their audience, they didn't use unremitting pain to do it. They used disability. The need for help to go to the toilet was the big stick. Wouldn't you rather die than have someone else wipe your butt? It never seemed to cross these advocates' minds that thousands of people in the United States get help to wipe their butts every day. Many of them are my friends. The blatant disdain and scorn that the assisted suicide advocates showed for people with real disabilities disgusted me. I began to see the smug slogan "Death with Dignity" in a new light: It hid the assumption that dignity was forever out of the reach of people who were disabled; "Better Dead than Disabled."

I admit that this was a gut reaction, not a reasoned argument. Imagine listening to a charismatic speaker, and then suddenly realizing that he was a racist, and he had almost convinced you to join him in a lynching! After that first gut reaction of disgust toward the ableism of the assisted suicide advocates, I looked more carefully into the policy and its implications. I now have a reasoned basis for my opposition to assisted suicide, and I have not changed my mind.

Gayle's Story

I graduated from college in 1987 with majors in history and philosophy. In 1992 I was teaching part time in the public school system and running my own home-based business tutoring and evaluating home-schooled students. These work arrangements were in place because I had a 9-year-old son and wanted to be home when he was home. That was the year my beliefs changed about assisted suicide. It happened literally by accident.

In September 1992, I was in an automobile accident. A drunk driver crossed the center line and crashed into my car. My passenger was killed. I received serious brain injuries, along with numerous broken bones and contusions. At first my condition was very frightening to those who knew me. I could barely recognize my family and could not remember anyone's name. My ability to speak was extremely limited because of aphasia, and my physical injuries made gesturing impossible. I was diagnosed with traumatic brain injury (TBI), a condition from which I am still recovering and with which I am learning to deal.

For many months after the accident I had trouble with both short-term and long-term memory. I had difficulty speaking and doing arithmetic. I had to learn how to read again. I also had a visual–spatial difficulty: I did not know where my body was, so I often remained quite still, not even gesturing. In the early days I had little concept of time, and 2 minutes was the same as 3 hours to me. As a consequence, from the "outside," it often looked as if there was nothing going on "inside" of me.

TBI had drastically affected my access to my own memories. Ordinary sensory experiences, like tastes and sounds, seemed unfamiliar. I couldn't recognize my house or my clothing. I couldn't even recognize myself in a photograph. (I could sometimes guess, though. In family photos I picked out the blond one as "me," because my husband's family is Okinawan and I am not.) For many months I got up every morning hoping I would recognize the person facing me in the mirror.

As bewildered as I was, I was still thinking. Once in the early days I asked my husband to bring a copy of Wittgenstein's *On Certainty* to the hospital (Wittgenstein, 1972). He would read to me from my bedside, and we would discuss Wittgenstein's philosophy (although my speech at the time was very hesitant and labored). This worried the nurses so much that they asked my husband to stop "because it is disturbing the patient to read this." I suppose they thought that because they found it disturbing naturally I would find it disturbing. Philosophical discourse is not familiar to everyone; I suppose they thought we were having a family dispute when we disagreed about epistemology. (Naturally, we continued discussing *On Certainty*.)

Ten years later, I still have difficulty with certain language tasks. I can't hear myself speak, for instance, and I often get tenses mixed up. I have difficulty with prepositions. (I noticed this while taking a French language course.) When I am tired, I have great difficulty in speaking. I have difficulty reading documents in certain fonts. Because of my visual–spatial difficulties I don't drive, and I don't cross busy streets or parking lots. I have learned to work with my impairments resulting from the TBI, and I have adjusted my lifestyle to let me do the things I want. It is an ongoing process, and I am still learning what accommodations will work for me. At first I struggled with asking people outside my family for accommodations. Now as a matter of course I use accommodations at home, work, and school. I don't really think about most of them anymore; they're just how I get along. They are no more "special accommodations" than the glasses that I have worn since I was 6 years old.

My approach to the physician-assisted suicide issue was completely changed by one single experience. It occurred right after my TBI and was the pivotal point in my interest in disability issues. In some sense it was an emotional reaction, but in another very real sense it was a philosophically reasoned change in view.

I was still in the hospital right after my automobile accident and sudden acquisition of TBI, going from one treatment center to another for innumerable tests. It is important to remember that TBI (and my inability to gesture) made it appear to some people that nothing was going on "inside" me. I found myself in a wheelchair in an elevator with two health care professionals. One woman was taking me to a set of medical tests. The other had joined us in the elevator. The first began to describe a car accident to the second person. She described the injuries, and the cognitive difficulties that occur with TBI. The other woman said, "You know, I'd kill myself if that ever happened to me. I don't want to end up like that."

Like what? I wondered. Then I realized that they were talking about me, right then, right there. It was my accident she was describing, and the second woman would rather die than end up like me!

I suddenly realized (with a shock) that I had completely missed a crucial aspect of the physician-assisted suicide issue. I had incorrectly assumed that the individual making the choice would be free from coercion and would be making a choice based on his or her own interests, free from the forced perspective of others. I had assumed that the choices being offered were indeed legitimate choices. Talk about fatal assumptions! Sitting in the wheelchair in that elevator, I realized exactly how fatal that assumption is: The very people whose job it was to care for me believed that I would be better off dead, and I was powerless to argue against them.

Fortunately, I never felt forced to "choose" physician-assisted suicide. But if it were a legal option, and if my caregivers shared the opinion of the woman in the elevator, and if my ability to defend myself remained as low as it was at that time, how long would I have been able to hold out against the pressure to "freely choose" suicide?

My first reaction was that I really was not in favor of physician-assisted suicide. There was an entirely different view that I had neglected to consider, and I was annoyed with myself, because I had so completely missed the point—that although we can allow people to make their own choices about life issues, those choices are often constrained by the values and opinions of the caregivers. (Well now, which do I choose? Life with what my family and society views as unbearable pain, uselessness, boredom, and indignity? Or do I choose to kill myself, heroically sparing my family and society the time and effort to care for me?) My previous belief in the moral rightness of assisted suicide was based on the value of choice above all. Now I realized that the more important issue was whether a truly free choice was actually being offered.

My second reaction was annoyance with those health care workers: "What do you know about what I find enjoyable and pleasurable in my life?" And because I felt secure in my situation with my own family and caregivers, "What do I care about what you think?" But the fact is, when you are dependent on someone for basic daily care, you have to care what your caregivers think. If you are fortunate, like I was and am, you will have caregivers who let you choose what is meaningful to your own life and then help you pursue it. Many people are not so fortunate. What about those whose caregivers have different criteria about what makes life meaningful or worthwhile? What happens when someone is dependent on caregivers who tell them "I would kill myself if I were in your situation," and then is offered a legal choice between physician-assisted suicide and a life that is "a burden to others" and "completely devoid of meaning"? What kind of choice is that?

Conclusion

"Your money or your life" is a forced choice, not a true choice, and neither is "Drive your family into bankruptcy or else accept assisted suicide." Or "Accept the help of caregivers who resent and despise your life, and would rather die themselves than live like you . . . and are willing to tell you that to your face . . . or else accept assisted suicide."

The reports from Oregon of legalized assisted suicide for the year 2002 show that pain is not the primary reason for wanting to die—It's not even in the top three. Reports were solicted from physicians of the people who had requested assisted suicide about which of six reasons might have contributed to the request. The reported reasons were were "losing autonomy (84%), decreasing ability to participate in activities that make life enjoyable (84%), and losing control of bodily functions (47%)" (Oregon Department of Human Services, 2003). George Eighmey, executive director of the assisted-suicide advocacy group Compassion in Dying of Oregon, makes it clear that disability phobia is the primary cause for death wishes. "The No. 1 reason given to me is: 'I don't want to have anyone wipe my rear end' (Robeznieks, 2003)." Given these statistics and public pronouncements, how could anyone maintain their self-respect and dignity and still be willing to live with a disability?

The typical arguments for assisted suicide are individualistic and personalized, based on the importance of individual choice over all else. They are flawed in two ways. First, they rely on the ableist prejudices of the audience: "Wouldn't you rather die than have someone else wipe your butt?" And second, the personalized form of the argument distracts the audience from recognizing that a social policy is being proposed. That policy amounts to a social endorsement of the correctness of certain suicide decisions, and we all know what those decisions are based on. Oregon has informed us: Ableist fear of disability, shame at needing help, dread of having someone else wipe one's butt.

Liberals are not usually fooled by individualistic libertarian arguments. "Wouldn't you want the right to choose who lives in your neighborhood?" sounds good, until we recognize that the result is racial segregation. Assisted suicide sounds good when it's personalized (at least to worried, ableist listeners). But when it's you whose life is being judged as suicide-worthy, the social significance becomes obvious. When Gayle realized that the woman in the elevator was describing here life as not worth living, her conversion was instantaneous.

Here is one aspect of the social significance of a policy of legalized assisted suicide: The level of federal funding to support people with serious impairments. The United States has a shamefully low level of such support, and the present administration is intent on reducing it further. Social policies that even appear to endorse the claim that disabled lives are not worth living affect the public perception of the people who live those lives. If such lives are not worth living, why should we waste precious tax dollars on their support? If people with serious impairments are forced to live in degrading conditions, so be it. The ableist's ideology justifies this decision: The unhappiness of "those people" is caused by their impairments, not by the ableist's own lack of social conscience. This is the social harm caused by ableism and abetted by the assisted suicide movement.

We (the authors) know all about the "safeguards" attached to assisted-suicide laws, such as the requirement for a terminal diagnosis. We do not trust them. For one thing, some of the leaders of the movement have made it clear that people with disabilities are the next step after people with terminal diagnoses (see Note). Second, the "safeguards" don't really make sense in themselves. If one were to consider death to be preferable to 6 months of disability, then surely one would consider death to be even more preferable to 50 years of disability. We oppose the premise that death is better than disability. The "safeguard" is just a quibble over the details.

We (the authors) have good news and bad news. The good news is that human beings are resilient. Young people often claim that they would rather die than get old. When they get old, they realize what fools they were when they were young. As oldsters, they are not obliged to commit suicide by their former lack of imagination about what makes life worth living. The same goes for acquiring a disability. It is possible for a person to create a perfectly delightful life under conditions that they never would have been wished for. Your previous, naïve lack of imagination ("I would rather die than . . .") is no barrier to the quality of your new life.

The bad news is that far too many people fail to recognize their own resilience. In their ableist pridefulness, many people are convinced that death is better than the loss of (what amounts to) their self-image—even in so trivial a matter as the self-image of a do-it-yourself toilet user. This tragic shortsightedness can result in suicides. Even worse, it can result in a social policy that implicitly endorses such grounds for suicide.

We oppose such a policy.

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AUTHORS' NOTE

"What can those of us who sympathize with a justified suicide by a handicapped person do to help? When we have statutes on the books permitting lawful physician aid-in-dying for the terminally ill, I believe that along with this reform there will come a more tolerant attitude to the other exceptional cases." Derek Humphry, *Final Exit,* p. 62.

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