

Better Dead than Disabled: The Perils of Social Devaluation, Assisted Suicide, and Euthanasia

It is not uncommon to hear people without disabilities, and people who recently acquired a disability, express they would rather be dead than disabled. Although politically incorrect, embedded perceptions that life with disability is full of suffering and indignity promote the idea that it's a death sentence. Able-ist social conditioning equates disability with pain, frailty, incapacity, and poor quality of life. It views persons with disabilities as problems that need to be fixed. I would argue the "problem" of disability lies more in external social, physical, attitudinal, and architectural barriers.

I am considered legally blind. If you hand me something in 12 point font, I can't read it. You might say I am disabled because I can't see. However, if you give me a document in large print, I no longer have a problem - an external change resolves a biological "shortcoming." At times I also use a wheelchair. I am "disabled" by the environment around me – stairs, curbs with no access cuts, and doors that don't open automatically. However, when changes are made externally, I become self-reliant.

Negative images devaluing persons with disabilities infiltrate literature, movies, news media and television. We are portrayed, at best, as having lives no one wants and, at worst, as freaks or deviants. Rarely are we depicted as empowered people with much to contribute to the world around us.

Unfortunately, many people who acquire a disability internalize able-ist perspectives. They see themselves as being of less value, rather than as people who have needs which, when accommodated, help them enjoy the same rights and responsibilities as every citizen.

Dignity and well-being are mistakenly equated with being able-bodied. Conversely, illness or disability is associated with lack of dignity. Dignity, a key component in actions before the Courts that seek to legalize euthanasia, is often defined by the notion that something like incontinency indicates a *lack* of dignity because it is perceived as a loss of autonomy. Although most people would not choose to be incontinent, toileting needs can be met through the assistance of another person or a disposable incontinency product. (Please note I'm not calling them diapers; infantilizing the people who use them only reduces their dignity.) But somehow, needing help to go to the bathroom is considered to have a greater detrimental impact on dignity than relying on other supports. Many people use eyeglasses. However, wearing spectacles doesn't lessen one's dignity, or even one's rightful place in the world. Donning an invisible incontinency product, on the other hand, seems a good reason to encourage someone to end it all.

Able-ist attitudes permeate our politics. Canada's current immigration policy restricts persons with disabilities from elsewhere to become citizens in our country. Someone like renowned scientist Stephen Hawking could be denied opportunity to immigrate to Canada based on this policy. I admire Dr. Hawking. He has not succumbed to the idea that because he has ALS, he has nothing left to offer. If a man who has made such significant contributions can't "make the cut," what message does that send? It says we don't really belong because we're not able-bodied.

Medical practitioners are not immune from these negative perceptions. Years ago, I initiated a conversation with my then endocrinologist about the possibility of pregnancy and how it would affect a woman with my disabilities. I wanted to have children, but also wanted to be responsible by getting fair and balanced information from an expert. My doctor's response was something like, "If people like you stopped having children, we could eliminate this disease from the face of the earth within a few generations." I don't know if he considered that eliminating "the disease" also meant eliminating people like me. For him, the problem was inside me, and following that logic, I was the undesirable component.

If we are tacitly acknowledged as unworthy, we are at risk. At times of fiscal restraint, we can experience discrimination when medical budgets are limited. It's very difficult to access information about how healthcare resources are allocated, but there is much evidence to support the idea that they are determined by measuring our value using subjective criteria like "quality of life." If medical practitioners don't have the direct experience of living with disability, and if they don't make extraordinary efforts to explore beyond the bio-medical models available in med student curriculum, how can doctors ever have anything but an able-ist evaluation of someone's quality of life? If our quality of life is viewed as being narrowed, we risk having our health options shrink. If our health options are taken away, or never presented in the first place, it threatens our very existence. It is especially in those times when we are coming to terms with new conditions, changing conditions, or physical and psychological pain, that we need to be reminded that we matter; that we are worth something. Our dignity is inherent. We have dignity because we are human. Our dignity is framed within the context of our sense of, contribution to, and interaction with our communities, not about what does or doesn't work in our bodies. If Dr. Hawking can add value to our society, we all can. We are only limited by our able-ist imaginations.

If assisted suicide or euthanasia is legalized, it could devastate persons with disabilities. Medical practitioners might never question the desire of someone who has acquired a disability to be euthanized because they won't consider that the requester is experiencing difficulty adjusting to a daunting change. Realistically, acquiring a disability is about living with loss – often requiring profound adjustment and supports, but so does losing a child. Do we hand grieving parents a hypodermic of lethal medicine and say, "This must be unbearable. Here's a way to end your suffering." Canadians seem enthusiastic

about promoting suicide prevention – but is that only for able-bodied people? When we face the social message that it's better to be dead than disabled, the option of assisted suicide and euthanasia rather than supports to help us live fully puts our very lives at risk.

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