



# Scholl Institute of Bioethics

# Bioethics Review

Vol 19 No 3

The Scholl Institute of Bioethics is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, physician-assisted-suicide, the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and the rights of disabled or mentally ill persons.

## Disability Rights Opposition to Assisted Suicide and Genetic Manipulation

By Skylar Covich PhD

In this essay, I discuss my personal observations of the blind community's approaches to life issues, and summarize the approaches that disabled activists have used to contribute to the case for life from conception to natural death. I write as one of these activists. Having been blind since birth, I was supportive of abortion and assisted suicide as a teenager, but after a conversion to the Catholic faith in college, I adopted pro-life views. Having earned my doctorate in political science from the University of California Santa Barbara, studied groups with an emphasis on religious organization, and become an activist as faculty advisor for UCSB's Students for Life chapter and then serving on the National Committee of the American Solidarity Party, I have become acquainted with diverse political perspectives including within the disability-rights movement.

Like many blind people, I approach general disability rights work with some care, and a slight distance. I have no other disabilities, and blindness itself does not involve the intense pain and constant medical interventions that characterize those with some other disabilities, and which result in much of the discussion around life issues for the disabled. That said, blind people have been involved in ethical debates around end-of-life care. Russell Kletzing (1925-2013), a former President of the National Federation of the Blind, favored assisted suicide, and though he never used blindness as a reason for assisted suicide, he became part of a coalition of disabled people who tried to discredit disability-rights opponents of assisted suicide as a loud minority, as can be seen here.

*"Blind people have been involved in ethical debates around end-of-life care"*

<https://www.deathwithdignity.org/death-dignity-people-disabilities/>

By contrast, Adrienne Asch (1946-2013) was a blind bioethicist who presented a secular case against testing for disabilities in fetuses and abortions resulting from such tests, and was sympathetic to disability rights cases against assisted suicide. I met Asch when I won a National Federation of the Blind scholarship in 2007, and regret that I was not academically mature enough as a college student to really work with her. The topic of pre-natal testing and genetic manipulation is likely to be of particular significance to blind people. Specialists have personally encouraged me to consider family planning measures that I believe to be unethical to assure that my blindness will not be passed on. Many blind people, as is also the case with deaf people, tend to focus on the specific and immediate needs of blind adults

and children. Meanwhile, other blind people, for the same secular or Christian reasons as anyone else, certainly adopt an entirely pro-life stance.

For anyone who is disabled and questions anti-life practices, empathy for the weak based on our own feelings of bodily weakness is likely to play a part in the transformation of our hearts. There are, however, three main schools of thought among disability-rights opponents of assisted suicide, prenatal testing, and genetic manipulation, which can result in coalition building across the left-right spectrum to stop specific practices: an intersectionality approach, a whole-life approach, and what I call a mainstream pro-life approach.

I would describe myself as at the conservative end of the whole life approach.

But these coalitions can result in tensions and even internal contradictions. Just as much of the Left was becoming supportive of assisted suicide, with the so-called Religious Right as the primary opponents of the practice, some disabled scholars and activists began making arguments against assisted suicide from a different perspective. Those taking an intersectionality approach believe that the availability of assisted suicide will result in the lives of the disabled being less valued. They point out that the health care system is inherently ableist, that many health professionals neglect the unique problems of the disabled and prefer to avoid the expense of continuing to treat them. The health care system is only one of the ableist aspects of society that makes life harder for the disabled, and the solution, for such activists, is to make life less painful to the disabled through a combination of attitude change among both the disabled and the general public, community development, and better government programs. The reason I refer to this approach as intersectionality is that to many of these activists ableism is just one social structure, and much of what can be described about ableism, such as our flawed health care system and social expectations, can also be described about sexism and racism. Regarding Adrienne Asch, many of the arguments about end-of-life care are also applied to pre-natal testing, and more recently to the prospect of genetic manipulation. You can learn more about the critiques of genetic manipulation by intersectionality-based disability rights activists here.

<https://www.geneticsandsociety.org/biopolitical-times/heritable-genome-editing-and-disability-rights-resources-teaching-and-learning>

However, key disability rights groups such as Not Dead Yet and National ADAPT are pro-choice or silent on the issue of abortion, as I explored in an article for the Society of St Sebastian,

<https://www.societyofstsebastian.org/copy-of-spring2019-roe-act-franks>

It is difficult to gauge the political impact of such discourse. Legislators who oppose assisted suicide seem just as likely to cite their religious faith or more general concerns about medical ethics to oppose assisted suicide, even while not applying these concerns to abortion. Some legislators have changed their votes after attempts are made to address disability rights putting safeguards in place to make sure that people are not pressured to undertake assisted suicide, but these do not address the core issues.

In addition to the failure of many in these groups to see the problems with abortion, I have some concerns about

placing disability rights as the primary reason to oppose anti-life practices, even while agreeing with many of the critiques of our social structures presented. There is, perhaps, too great of an opening for a re-evaluation particularly of end-of-life options if activists were to see enough improvement in social structures. I am also concerned that some disabled activists embrace their disability as a core aspect of their identity, and seem uninterested in preventing disability. Certainly, it is unhealthy to be too obsessive about finding cures that may never come. It is also wrong to undertake cures or preventative measures that are unethical, and I do believe that genetic manipulation is unethical because of the broader consequences likely to result for humanity. I prefer to think of the suffering and limitations of disability as a cross, rather than anything to celebrate, while seeking to understand the moral course almost as if I were not disabled.

There are groups, however, who do apply most of the intersectionality approach, while taking a consistently pro-life (also called whole life, consistent life, or in Catholic circles, seamless garment) position, including broad opposition to abortion. The largest whole life organizations include my own American Solidarity Party, New Wave Feminists, Democrats for Life, Rehumanize International, and the Consistent Life Network; CLN is an older group of which all these organizations and many others are members. Rehumanize probably places the greatest emphasis on disability rights perspectives, with talks focused on ableism and suicide prevention prominently placed on their recent annual conferences. Disabled whole-life activists are diverse, with some taking a similar avowedly secular approach as Not Dead Yet, while others are outspoken about their religious faith while indicating that secular arguments are of great importance.

Finally, there are many pro-life activists who happen to be disabled, and may include disability outreach in their work (the evangelical group Joni and Friends is perhaps the most significant example), but who embrace the pro-life cause for reasons outside of themselves. I tend to take this approach. However, I do embrace the whole-life approach because I agree with its concerns for economic justice, peace, environmental protections, an end to the death penalty, and an end to American involvement in foreign wars. I also recognize that my testimony as a disabled person can be important when taking up pro-life outreach, by explaining how we can come to such a position despite the physical limitations and sometimes social marginalization that we face.

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