

The Implications of Embryonic Stem Cell Research on Those with Disabilities

Stem cell research has the potential to open up life saving technologies to the chronically ill and those with genetic diseases. The alleged promises of such astounding medical advances that stem cell research can provide are grand and have a long road of development ahead. Despite this ongoing developmental stage, the effects of this research are already being felt in many politically oriented groups, most notably those who are adamantly for or against stem cell research. More particularly, the effects of this research is being felt by those groups who are involved with ethical standpoints involving such research. The opinion of one group that seems to be overlooked is that of the disabled community. Just as many other activist groups are involved with ethical issues surrounding such scientific developments; those with disabilities that could potentially be “cured” with this research are not being adequately heard.

Just as with any other political activist group, there are many varying opinions within the group. The disabled community is by no means any exception. I will attempt to summarize and bring to light some of the viewpoints I have encountered while exploring social implications of stem cell research and potential “cures” on the disabled community.

First let me examine the position of the disabled not as a politically active interest group, but as a minority that is seen by the medical community as something that needs a

“cure”. Those that fall into this category may see stem cell research as an infringement on their human rights. In an online article by Larry Elder, the hypocrisy of Bush’s approval of “funding for limited embryonic stem-cell research” and his simultaneous praise of the American’s with Disabilities Act took many by surprise.ⁱ Such a mandate to allow for federal funding to take action towards “curing” and even possibly eradicating disabilities from society completely counters the progress the ADA has taken 11 years to make. The subtle beginnings of resurrecting a new form of eugenics takes a hard stab at the livelihood of the progressive reform that has been made from laws protecting those with disabilities. A resounding echo of resentment of research development follows such an idea with foundations rooted in “finding a cure”. As Leipoldt states:

When scientists talk about curing the usual swathe of conditions, including spinal cord injuries, Alzheimer's and Parkinson's disease, they often take a warped view of living life with a disability. Not only may they describe such conditions as an intolerable burden for society but some are as arrogant as to foreshadow that "we may be able to produce a whole generation of people who have a pretty good quality of life right up until they die" (Professor Rathen, "Laws hamper stem cell research", *The Australian*, September 2, 2005).ⁱⁱ

This stereotype of the lives of those who live with disabilities is far more disabling than the condition itself. If the lives of the disabled are perceived as being a constant struggle and not worth living, all of the power behind disability related legislation is siphoned out and the assumptions that death would be better than disabled are used to fuel legislation that will bring medical research steps closer to a cure.

Not only is stem cell research dealing directly with issues of health affecting conditions, the sciences are dabbling more and more determinedly into the realm of controlling basic characteristics of a fetus not necessarily related to health issues. Determining the sex of a fetus before it is determined by the state as viable, opens up the possibility of a cheaper abortion if the result is not the desired one. This economic incentive of early determination of sex is beneficial to the individual, however, the overarching idea behind such ease of sexual selection is also creeping into the realm of normalization of the human race. As pointed out in an article on sexual selection: “a sperm sorting service that selects for sex before pregnancy, [is] part of an ongoing commercial effort to normalize sex selection as Extreme Makeover normalizes cosmetic surgery”.ⁱⁱⁱ The attempt to determine and “fix” a child’s characteristics, even if they are not of a medical concern, denotes the beginnings of misuse of such a strong science and transformation into a practice that may be closely related to racial cleansing or purification. The simple option of elimination of not only life altering diseases but of random sex selection opens up a Pandora’s box of normalization that will inevitably bring society closer to a dull homogenous mix and undoubtedly increase prejudice of those who deviate from the new normal as determined by medical science.

As a political group, the disabled community has varying views on the potential effects of stem cell research. Some see the potential for a “cure” to their own medical conditions a welcome adjustment to their quality of life. Most famously, Christopher Reeve as well as many other celebrities were quoted as having a strong faith in the benefits of embryonic stem cell research on the cure for their disabilities:

Michael J. Fox has testified before Congress saying he believes this research could help cure a disease he has, Parkinson's. Mary Tyler Moore has gone before the Congress and said perhaps in stem-cell research, including embryonic stem cell-research, is the cure for diabetes.^{iv}

Many of those who are affected to some degree with a condition that could be potentially helped by embryonic stem cell research are enthusiastically in support of advances, but are also morally conscious of ethical issues regarding the harvesting and use of the stem cells used in such therapies. Some feel as if stipulations must be put on the methods and practices involving gathering of cells. Some say they will only support the advancements in the light of humane and ethical treatment of both the stem cells as well as any other person involved in the research. By overlooking the ethical issues surrounding the gathering of cells, some with treatable conditions would not feel morally in tune with the treatment options and do not view such an option as a treatment for their condition.

Despite many promising advances in embryonic stem cell research, the attitudes of those with such medical conditions are also an important factor in deciding the use of such treatment and its funding. The attitudes of medical practitioners towards those with disabilities and assumptions of a poorer quality of life is the driving force for much of its development. This kind of attitude will ultimately lead to important treatments in medicine. However, the social construction of disability should not and cannot be overlooked in the decision to medicalize and treat those with disabilities. This symbiotic relationship between disabling stereotyping and medicinal advancement has not been examined as an influencing factor on the advancement of stem cell research.

ⁱ Elder, Larry. "Say No to Federal Funding for Stem-Cell Research." Capitalism Magazine. 20 Aug. 2001. 30 Apr. 2006 <<http://www.capmag.com/article.asp?ID=1030>>.

ⁱⁱ Leipoldt, Erik. "Embryonic Stem Cell Research: a Sob Story?" Online Opinion. 14 Sept. 2005. 30 Apr. 2006 <<http://www.onlineopinion.com.au/view.asp?article=172>>.

ⁱⁱⁱ Obasogie, Osagie K. "Designing Your Own Baby, the Boston Globe." The Boston Globe. 8 Aug. 2005. 8 May 2006

<http://www.boston.com/news/globe/editorial_opinion/oped/articles/2005/08/08/designing_your_own_baby/>

^{iv} King, John. "Christopher Reeves on Politics and Stem Cell Research." CNN.Com. 30 July 2001. 8 May 2006 <<http://transcripts.cnn.com/2001/ALLPOLITICS/07/29/reeve.cnn/index.html>>.