States of Denial: Recognising Difficult History, Strengthening Our Future

Nancy Hansen, PhD,Assistant Professor, Interdisciplinary Master's Program in Disability
Studies,Room 128, Education Building,University of Manitoba
Winnipeg, MB Canada R3T 2N2
(204) 474-6458 E-mail: hansenn@cc.umanitoba.ca

Introduction

In July 2004, I was chosen as one of fourteen international scholars to participate in an Einstein Summer Institute held in Berlin. *Disability Studies and the Legacies of Eugenics* marked the first time that English-speaking academics with disabilities had the opportunity to study disability, eugenics and the Holocaust in Germany. Little did I know that this four-week fieldwork exercise would have such a profound personal impact on my own research trajectory.

Almost 250,000 disabled people were murdered during the NAZI genocide in Germany and the occupied countries (Evans, 2004) Yet, our place in this awfulness remains largely unknown and unmarked. The inaccessible sites of extermination are left untouched as though there were nothing to explain, condemn, or mourn. Inclusion and exclusion is not a simple duality: they can coexist. This subtle but collective aversion manifests itself in many ways and on several macro and micro levels simultaneously. It is as if Western society retains a palpable level of indecision in relation to the worth and validity of nonconformist minds and bodies.

Few of the thousands of perpetrators were ever caught or prosecuted (Evans, 2004). Disabled people and their families have not received compensation as a result of these atrocities (Malhotra, 2001).

Only after these spaces were reclaimed by the disability community in the late 1980s has the research begun (Kerr and Shakespeare, 2002). Governments have been reluctant to allow access to or translation of historical materials (Snyder, 2004). Even amongst disability scholars Holocaust research seems to create contention (Shakespeare, 2005).However, failure to critically engage with difficult histories may have serious consequences for the disability community in the 21st century. There are disturbing similarities in arguments found in NAZI documentation concerning ‘quality of life’, ‘useless eaters’ or ‘lives less worthy’ and mainstream genetics and medical ethics discussions concerning disability taking place today (Evans, 2004). This paper explores the various challenges in the process of knowledge reclamation and how shifting perspectives can valorize historical memory.

Knowledge of the disability studies’ academic paradigm is particularly critical to scholars of German Studies, History, Human Geography and Culture attempting to understand trans-Atlantic eugenics and the role of disabled people in the Holocaust.

While a significant body of historical research has been produced on the treatment of other minority communities during the Nazi regime, research on disabled people has only recently surfaced as an important aspect of efforts to comprehend the nature and mechanisms of German fascism during the 1930s and 1940s. This attention to disability issues has been the result of work by international and German disability studies scholars who have sought to redress medical models that have led to devastating consequences and stigmatizing attitudes for disabled people. (Snyder, 2003)

Background

During the Nazi regime 1933-45 progress and modernization were framed without non conformist minds and bodies without disabled people. Adopting the eugenics philosophy that was popular throughout Europe and North America at the time directed toward the elimination of these conditions: blindness, deafness congenital, psychological or epilepsy cognitive disability alcoholism or sexual orientation (Mitchell and Snyder, 2002)

In Britain and North America eugenics was comprised of two elements segregation or incarceration and sterilization. Nazi Germany went one step further to extermination. It should be noted that death rates following institutionalization were high in the range of 10 to 20 percent. This policy was 'justified' on the basis of lack of individual utility and economic viability as represented by disabled people (Mitchell and Snyder, 2002).

T-4

The T-4 program as it was euphemistically known, was named after Tiergartenstrasse 4, Berlin the location where the policy was first developed. Between 1940-1942 71,000 Disabled people were murdered and by the end of World War II 240,000 disabled people were killed in the interest of science. Health care providers were required to register people whose bodies and or were deemed undesirable. Selection and registration was done on a highly subjective and arbitrary basis. Few people were aware of what the consequences of registration would be:

- There were 6 killing sites in Germany Brandenberg, Bernberg, Hadamar, Gravenek, Sonenstein and Hartheim and others were located in NAZI occupied territories
- Gassing, starvation, or overdose
- Training ground for concentration and death camps
- Prior to going to the gas chamber victims were photographed from all four sides and examined by a doctor to determine a suitable 'cause of death' for the false death certificate (because much of the documentation falls under 'medical records' although information is falsified it remains protected in the present day as 'medical documentation')
- People were also marked with numbers signifying interest for autopsy or tooth extraction for gold fillings
- 75 people were killed at each gassing and death took approximately thirty minutes

(Synopsis from *A World Without Bodies,* Mitchell and Snyder 2002).

Reclamation and Memorial

Unlike the work camps and death camps that were destroyed by the retreating or liberating forces, disabled killing sites have been left largely undisturbed. They remained untouched save the disconnection of the gas and removal of ovens that were used at death camps like Auschwitz. Reclamation of the killings sites as archives and memorials only took place in the late 1980s after intense lobbying by German disability rights groups

(Mitchell and Snyder, 2002). In fact many of the killing sites are located in the midst of functioning psychiatric and correctional institutions. Few people involved with the killing sites were ever prosecuted and the longest sentence was 18 months (Mitchell and Snyder, 2002) At one court proceeding which resulted in an acquittal the defendant simply referred to his victims as “burnt-out human husks” quoted in (Evans, 2004 at p.148).Many physicians involved in the killing process kept specimen body parts and went on to build respected careers in biological science working with disabled people (Mitchell and Snyder, 2002 ; Köbsell**,** 2004).

Today the information gathered from ‘specimens’ collected are still being used by medical schools and they have provided the framework for modern biology. Much of modern biology has quite literally been built on the backs of disabled people (Mitchell and Snyder, 2002).

The plight of disabled people during the National Socialist period in Germany is largely absent from the ‘public consciousness’ for the most part remain ambivalent. Many are reluctant to acknowledge this messy, ugly reality. Few memorials acknowledge that disabled people were victims of genocide and Most of the victims records remain sealed and off limits to researchers. For despite containing falsified health reports and causes of death they are still nonetheless considered ‘health’ records and subject to privacy legislation. Archivist have made efforts to have materials available in other formats but accessing funding has been a daunting project in light of budget cutbacks (George, 2004a). Most sites remain physically inaccessible with long flights of stairs and inaccessible materials. To date what funding is available for these efforts has come largely from other E.U. member countries (George, 2004b).

Making Space for Difficult Scholarly Research: Why Study the Holocaust?

There has been a tendency to relegate Holocaust research to an important element in 'Jewish history' or treat it as some sort of historical social abhorrent or 'special interest' that has been effectively dealt with (Bauman, 2000). Such an approach, keeps the social discomfort level at arms length and thereby maintains the belief that we need not revisit this ugly history in a modern context (Bauman, 2000).

Bauman (2000) postulates that the most valued elements of modern Western society were all present:

> "all those many things that rendered it (the Holocaust) possible- were normal …in the sense of being fully in keeping with everything we know about our civilization, its guiding spirit, its priorities, its immanent vision of the world – and of the proper ways to pursue human happiness together with a perfect society" p.8.

Similarly at p.13,

> "its technology, its rational criteria of choice, its tendency to subordinate thought and action to the pragmatics of economy and effectiveness" p.13.

This perspective runs contrary the sense of security provided by the 'failed state' analogies. Thus, we are faced with functioning states that may choose to no longer provide space for what some perceive as 'failed' minds and bodies. Technology is not benign certain notions of the body underscore the debate (Bailey, 1996; Corker and Shakespeare, 2002). However, noted disability studies scholars are profoundly reluctant to engage with the topic on any level and poorly informed on the topic for example:

> it's important to remember that the vast majority of disabled people killed by the Nazis were people with intellectual impairments or mental illness - i.e. people who were institutionalised in the first place - not disabled people living in the community. I have a physical impairment myself, and while people like me may have been sterilised, I believe it's the case that we made up a minority of those who were killed (except for those who were also targets for other reasons, for example being Jews). …it's the ultimate authenticity - which I think is problematic - it's sometimes about positioning

> ourselves politically and rhetorically, which I think is not the right reason to dwell on these sad issues …
> (Shakespeare, Email February 1, 2005)

There is a disturbing sense of disability and impairment hierarchy evoked when one relies on community location and nature of impairment as a form of social distancing and protection. One can be and feel competent and in control until those in power decide otherwise. (Lutfiyya**,** 2005) Everyone is vulnerable to some degree but there are some individuals who are more vulnerable because of social positioning and public perception and how those perceptions are acted upon. (Lutfiyya**,** 2005).

Echoes from the Past

According to Evans (2004) In 1939 Dr. Theo Morel, Hitler's personal physician put forward the policy recommending:

Killing people who suffered from congenital mental or physical "malformations" because such "creatures" required long-term care, aroused "horror" in other people, and represented the "lowest animal level"(Evans, 2004, p. 24-25). Strikingly similar medical ethicist Peter Singer (1995) proposes "to embrace a social ethic where some human lives are valued and others are not.' (Singer, 1994, p.121).

The perceptions and opinions of disabled people are rarely given space where these debates take place (Walbring, 2002).

As a society we have yet to develop a comfort level with the 'messiness' that constitutes humanity. There is often a tendency to conflate quality of life with worthiness to live. Community membership space, or the state of belonging or not to communities, may be determined, in part, by socially defined identifiers of acceptable physicality or intellect

Socially ascribed markers determine degrees or levels of inclusion, and the presence of disability seems to challenge the accepted markers of humanity or normalcy. Social assumptions, including reactions to perceived differences, appear to hark back to ancient belief systems ingrained deep within the collective social consciousness, ones arguably rooted in fear and limited knowledge (Hansen, 2002).

Thus, at the beginning of the 21st Century we as disabled people are often faced with an interesting paradox. We have acquired more social acceptance than ever before as numerous pieces rights legislation attest (Mostert, 2002). Yet at the same time, disabled people and their allies are regularly placed in a situation of having to justify access to treatment and the right to live on the basis of individual economic and social utility at either end of the life continuum (Mostert, 2002).

A question of Perspective the New Genetics/eugenics research?

It is telling the bulk of research itself remains within the scope of the non-disabled. Having the opportunity to engage with German academics from various universities and research centres and community leaders disabled and non-disabled alike brought further depth and dimension to the research process. Going to the Institut Mensch, Ethik und Wissenschaft was an excellent way to illustrate how lessons from the legacies of eugenics are used and can serve as a critical lens to examine genetic research today.

There has been an increasing tendency to conflate genetics and eugenics (Kerr and Shakespeare, 2002). Increasingly, the complexity and diversity of humanity are framed as a series of ‘problems’ to be dealt with (Kerr and Shakespeare, 2002). The perspective presented in the mainstream is often oversimplified as if we are all ‘products of genetic determinism’ (Kerr and Shakespeare, 2002). The rationality of science provides the impression of impartiality and equilibrium (Kerr and Shakespeare, 2002). However, past practice and strongly engrained social beliefs may have a profound impact on the development focus and direction of research (Mostert, 2002) One is constantly amazed and appalled by the absence of disabled people repeatedly absent, silence and a depiction of stilted, primitive simplicity, of much disability research arguably grounded in fear (Hansen, 2002).

Technology and Destiny

Cultural understanding provides the framework by which technology introduced and understood (Kerr and Shakespeare, 2002). In many ways the determinist view of technology and disability reflects elements of the medical model, as it holds out a technological ‘fix’ as the latest panacea to integrate disabled people into mainstream society (Sheldon, 1998). Increasingly, we as a society are pressured to comply with majority understandings related to genetic testing and technology under the umbrella of ‘progress’ and cure (Kerr and Shakespeare, 2002).

Failure to do so runs the risk of some form of social sanction and this perspective is rarely if ever subjected to critique. The growth of technology is presented as positive and benign (Kerr and Shakespeare, 2002) Where thought is given to reshaping, all too quickly technology is held out as the ultimate solution, often to the detriment of considering more modest solutions addressing questions of time, space and social attitudes (Hansen, 2002).

Human beings are far more complex than our genetic make-up (Kerr and Shakespeare, 2002). In reality less than two percent of impairments are the result of genetic difference. At present, over 90% of tests that identify Down Syndrome result in termination of pregnancy (Mansfield, 1999). Yet, many individuals having Down's do not self- identify as impaired (Buckley, n.d.).

Technological developments are having a profound impact on the lives of disabled persons both in terms of service access and delivery (Mostert, 2002). We must begin to examine technology in the context through which it has developed recognizing that it framed by market forces that are driven by social and cultural subjectivities (Kerr and Shakespeare, 2002)

Conclusion

As far as the Holocaust and disability there are many layers of complexity. What is of importance here is that policies condoned killing of disabled people or anyone for that matter. This discussion is not about numbers, or politics or rhetoric. It is about policies that excuse killing people. It is perilous to think one is always in control there is no risk.. People do not like to think of personal vulnerabilities no matter what group one falls into. With this in mind, must begin to address messy and complex diversity that is the very essence of humanity . As technology develops, we must ask ourselves the difficult question, Is the neutrality of science solidifying established social practices? This may crowd the comfort zone of the academy. But to quote Leo Baeck *Nothing is so sad as silence.* Our future depends on a robust yet balanced discussion that finds disabled people and their allies at the centre.

References

Bailey, R. 1996, Prenatal Testing and the Prevention of Impairment: A Woman's Right to Choose. In *Encounters With Strangers: Feminism and Disability,* ed. .J. Morris. Women's Press, London. pp.143-167

Bauman, Z. 2000, *Modernity and the Holocaust.* Cornell University Press Ithaca

Buckley, S. *Living with Down syndrome* in Down Syndrome Information Network

http://www.down-syndrome.info/library/dsii/01/01/DSii-01-01-EN-GB.htm

Mansfield, C. Hopfer, S. Marteau, T. 1999, *Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review* in Prenatal Diagnosis, Vol. 19, No. 2, pp. 808-812

Corker, M. and Shakespeare, T. 2002, Mapping the Terrain In *Disability/Postmodernity Embodying Disability Theory,* M. Corker,. and T. Shakespeare, eds., Continuum London pp.1-17

Evans, S.2004, *Forgotten Crimes: The Holocaust and Disabled people*. Ivan R. Dee, Chicago

George , U. 2004a, E-mail Hadamar Memorial October 27th 2004

George, U. 2004b, E-mail Hadamar Exhibit Funding December 9th 2004

Hansen, N. 2002, '*Passing' Through Other Peoples' Spaces: Disabled Women Geography, and Work.* Unpublished PhD. Thesis, University of Glasgow, Glasgow, Scotland

Kerr, A. and Shakespeare, T. 2002, *Genetic Politics: From Eugenics to Genome*. New Clarion Press Cheltenham

Köbsell, S. 2004*, History of the German Disability Rights Movement*" July 21 at Disability Studies and the Legacies of Eugenics, Potsdam Germany

Lutfiyya**,** Z. 2005, E-mail February 1, 2005, Associate Dean (Research and Graduate Programs)/Professor Faculty of Education University of Manitoba Winnipeg Canada

Malhotra, R., 2001,*The Politics of the Disability Rights Movement.* Internet http://www.zmag.org/content/print_article.cfm?itemID=2146&sectionID=47 pp.1-9

McPherson, G. and Sobsey D. 2003, Rehabilitation: *Disability Ethics Versus Peter Singer*. In Arch. Phys Med. Relabil. Vol.84, August. pp.1246-48

Mitchell, D. and Snyder, S 2002. *A World Without Bodies,* Brace Yourselves Production, Chicago film

Mostert, M., 2002 *Useless Eaters: Disability as Genocidal Marker in Nazi Germany*. The Journal of Special Education. Vol.36, no.3, pp 155-168

Shakespeare ,T. 2005 , E-Mail February 1, 2005 PEALS Bioscience CentreTimes Square, Newcastle

Sheldon, A. 1998, *Disability Technology and Social Change: the Case of Information and Communications Technology*. Paper presented to Disability Studies Seminar- Disability and Social Policy Past, Present and Future Edinburgh December 2-4.

Singer, P.1994, *Rethinking Life and Death: The Collapse of Our Traditional Ethics.* St. Martin's Griffin, New York

Snyder, S, 2004, Director's Report, *Disability Studies and the Legacies of Eugenics*

Wolbring, G. 2002, *Rationale for the Establishment of an International Center for Bioethics, Culture and Disability.* Internet www.bioethicsanddisability.org , 9/11/2002 pp.1-5