

# THE DISABILITY HISTORY NEWSLETTER VOLUME IV, SPRING 2008

Dear DHA Members,

This Spring 2008 issue contains a message from the President, information about various upcoming events of interest to historians of disability, news of recent scholarship, and profiles of two DHA members, one from Germany and the other from India.

As always, please feel free to contact Cathy Kudlick with information or suggestions for articles for future newsletters: <a href="cjkudlick@ucdavis.edu">cjkudlick@ucdavis.edu</a> In the Fall Newsletter look for my interview with A History of Disability author Henri-Jacques Stiker.

#### FROM THE PRESIDENT

If I had time to write blogs and you had time to read them, you would have known that I spent the first two months of 2008 traveling to various blind school archives in Paris and along the east coast of the United States. It was an exhilarating, but also sobering trip. I thoroughly enjoyed going to places where nobody expressed concern or puzzlement that I was interested in *those people*. I also appreciated not having to explain my access needs, how I do things, why I need to pull out every book and hold it close to see what's inside, while armed with magnifier and digital camera. And nobody gives better directions for getting places than people at blind schools! Finally, I benefited from amazing hospitality, lodging on the school grounds for almost nothing, eating in various cafeterias, eavesdropping on staff, teachers, and students.

Even though I was lonely and sometimes wondered if the places I stayed were haunted, I considered myself one of the lucky last visitors to a vanishing world. There was something innocent about these places that would take in a stranger, give her shelter and food for both mind and body. Of course I came credentialed, with my PhD and job and privilege. And I had zero nostalgia for such places as I fought off the vague nausea that comes with breathing the air of paternalism. (Was it my place to launch into a philosophical debate with the blind guide in his early sixties who led me and a Girl Scout troop on a blind-folded tour of the museum?) Still, it felt genuine, not corporate or polished, not manicured and manipulated or hip. Not since my first days as a grad student in the French National Archives did I feel as connected to the history I was studying. With the increasingly posh, computerized, catalogued, regulated, differentiated, stratified, packaged research facilities taking over, there's seldom the sensation that the nineteenth-century eccentric who wrote the letter you're reading is standing over your shoulder egging you

on. All of this was possible because time has forgotten the blind schools and especially the blind school archives.

But for this same reason the archives are in great danger. At one place that had been one of the most important institutions of blind history, I was shown an attic so filthy and neglected that pages crumbled simply because I opened the door. They didn't have money for an archivist, so an overworked teacher who happened to love history was coping as best he could. At another place—this one extremely well cataloged and neat—late nineteenth-century newsclippings turned to dust in my fingers. In the best places the poor librarian/archivist had so many other responsibilities that materials piled up, queries went unanswered, and budgets were cut and cut again. It isn't hard to imagine a siege mentality in which space, time, and humanity have been so compressed that the air has been sucked out. Very few understand the problem. The vast majority of people in the modern world think that history is useless and irrelevant. And fewer still give one iota about the blind. So the history of blind people seems like a Venn diagram that pinpoints the epitome of insignificance.

And yet, as president of our emerging DHA, I carried you and your fellow members with me. I took comfort in being able to hold my head high, knowing that a group of people finds this work not simply interesting but also important. It was so empowering to tell archivists, directors, scholars, kids at blind schools, and even complete strangers at bus stops that I represented the beginning of something new, that there are scores of us around the world undertaking this work. As we all struggle to find time and money to do what we do, take heart that we are finding one another and are making history in the very act of writing it.

And there is much work to do. In addition to convincing the greater world that this history has value, we need to embark on a campaign to preserve the documents and support places where they might reside. We must lobby at the local and state level, work with communities and individuals, as well as with national and international organizations. We must keep abreast of deaths, institutional relocations and closings, and any other events that might yield documents and artifacts. And we must begin the complex task of cataloguing what exists so that others may benefit from these documents.

Our past is our future. Together we will make it happen.

#### DHA & AHA

The American Historical Association has at last made the formal appointment of a Task Force to deal with disability issues. The Professional Division will provide three members and DHA two: yours truly, and DHA Board Member Professor Paul Longmore of San Francisco State University. The Task Force will meet for the next three years to hammer out a set of policies and best-practices for the AHA to follow in order to advance disability history as a scholarly field and to create a more welcoming profession. As I have said on more than one occasion, the AHA has considerable clout to influence policies at all levels of the history profession, from K-12 teaching content to tenure and promotion practices at our universities.

We need your feedback about anything you would like to have DHA bring to the table. Please feel free to contact me: <a href="mailto:cjkudlick@ucdavis.edu">cjkudlick@ucdavis.edu</a> or Paul: <a href="mailto:longmore@sfsu.edu">longmore@sfsu.edu</a> with any suggestions, comments, hopes, fears, cautions, jokes, etc.

#### **DHA & Upcoming Conferences**

1. **The Berkshire Conference of Women Historians,** Minneapolis, MN, June 12-15, 2008 (<a href="http://berks.umn.edu/index.html">http://berks.umn.edu/index.html</a>). Come to the DHA reception on Friday, June 13 from 6:00-7:30 at the Minnesota Room in the McNamara Alumni Center (where the main reception for the conference will be held).

For a list of panels of interest to disability historians, Board Member Penny Richards has provided the following list:

#### **PANELS:**

[46] Disability History Confronts Women's History: Compliant Daughter or Rebellious Youth?

Chair: Susan Burch (Ohio State U.)

- Susan Burch (Ohio State U.): "What's the Sign for Sex? Changing Views of Language, Gender, and Historical Identity in America's Deaf Community"
- Penny L. Richards (UCLA-Center for the Study of Women): "The Spinster in the Attic: Retrieving Disabled Women's Stories from Private Collections"
- Kim Nielsen (University of Wisconsin-Green Bay): "Confessions of the Right-Now Able-Bodied Researcher"
- Audra Jennings (Ohio State U.): "The Forceful Urge for Independence: Women Activists and the American Federation of the Physically Handicapped, 1942-1960"

[105] How Do They Do It? Sexual Representations of Conjoined Twins in United States Culture

Chair: Ruth Alexander (Colorado State U.)

- Ellen Samuels (University of Wisconsin-Madison): "Examining Millie and Christine McCoy: Where Enslavement and Enfreakment Meet"
- Alison Kafer (Southwestern U.): "Fabulist Past, Fabulist Future, but No Queer Presence: Desiring Disability in Shelley Jackson's 'Half-Life'"
- Cynthia Wu (SUNY Buffalo): "The Queer Pleasures and Frustrations of Chang and Eng's Autopsy"

Comment: Catherine Kudlick (UC-Davis)

#### **INDIVIDUAL PAPERS:**

• Ryan Lee Cartwright (University of Minnesota-Twin Cities): "'Feeble- Minded' Women and Country Rubes: Intersections of Sexuality, Race, and Mental Ability in the Rural United States" [38]

- Sarah Rose (University of Illinois, Chicago): "Preventing the Reproduction of Dependency: Women in Idiot Asylum Labor Programs, 1878-1920" [59]
- Susan Rensing (Mississippi State U.): "Sexual Eugenics in Progressive Era America" [63]
- Ana Carden-Coyne (Manchester U.): "Conflicted Bodies: Gendering Pain and Injury in Wartime"
- Lisa Kohlmeier (Claremont Graduate U.): "The Space of the Sickroom in the Life of Alice James" [68]
- Jennifer M. Morris (College of Mount St. Joseph): "Degenerates No Longer: UN-ICEF's Anti-Syphillis Campaign" [180]
- Aimee Newell (U-Mass, Amherst): "Tattered Pieces: The Sampler of an Aging Antebellum New England Woman"
- 2. **Society for Disability Studies,** New York City, USA, June 18-21, 2008 (http://www.disstudies.org/conference/2008).

For a list of panels of interest to disability historians, DHA Board Member Penny Richards has provided the following list:

A Workshop in the Works: "Doing Disability Community History"

- Susan Burch
- David Serlin
- Jean Lindquist Bergey
- Diane Britton
- Ray Pence

Immigrants and Others: Disability and the Nation

- Sagit Mor, "Neglected Stories: Disability, Immigration, and National Imagination."
- Jay Dolmage, "The Golden Door: Eugenics at Ellis Island."
- Shaista Patel, "Maddening the Racialized Terror: The Insane Muslim within Canadian Nation-Building."
- Douglas Baynton, "Defect, Ethnicity, and Appearance: Disabled Immigrants in the American Imagination."

Disability and the War in Iraq: Disabled Veterans, History, and Culture

 David Serlin, "Performing Disabled Masculinities at Walter Reed from WWII to the Iraq War."

- Ellen Samuels, "Narrative Invalidity: From Gulf War Syndrome to the Iraq Vet Borderline Personality Scandal."
- Megan V. Davis, "Images of Sovereignty: Disabled American Soldiers and the Excesses of US Global Imperialism."

Respondent: David Gerber

## **Individual papers of interest:**

- Andre Cormier, "'She's Lame! O!' (U 351) The Female Body, Disability, and Irish Colonial Pathology."
- Dominika Bednarska, "Critique Through the City: Examining Ideologies of Gender and Disability in Woolf's Mrs Dalloway."
- Melanie Wakefield (Michigan), "Diagnosing Virginia: the Dialectic of Madness in Virginia Woolf."
- Sara Scalenge, "Blindness in the Arab-Islamic World: A Historical Perspective."
- Kristen Harmon, "Something Secret and Superstitious': Deafness and Gender in Wilkie Collins's Hide and Seek."
- Jennifer Nelson, "Bearing the Word: Linguistic Colonialism in de Musset's Pierre and Camille."
- Zosha Stuckey, "Lavinia Magri and the Rhetoric of Civic 'Fitness' in 19th Century Freak Shows."

#### **Posters:**

- Corbett O'Toole, "Why Berkeley? Independent Living Origins"
- Justin Powell and Liat Ben-Moshe, "Symbolizing Accessibility: Revis (it)ing the International Symbol of Access."
- Gail S. Werblood, "Frida Kahlo Visits the Big Apple: Memoirs of Experience in New York City"
- 3. **Disability History: Theory and Practice,** San Francisco State University, July 31-August 3, 2008.

San Francisco State University's Institute on Disability, the Disability History Association, and the Disability History Group of the United Kingdom will jointly host Disability

History: Theory and Practice, a conference at San Francisco State University, 31 July-3 August 2008.

During the past two decades, research, teaching, and scholarly publication on the history of disability as a social, cultural, and political phenomenon have drawn increasing attention. The goal of this conference is to assess the state of the field. It will examine the theory and practice of disability history. And it will explore theoretical and substantive, methodological and practical strategies to promote the continued development and intellectual coherence of this field.

While the more than four dozen papers are diverse in subject matter, we intend that the presenters, commentators, and audience participants will use these historical case studies to open up discussion of broader issues. We will consider how scholars approach the history of disability. What theoretical concepts inform our interpretations? What analytical and methodological tools do we find most useful? How does our work benefit from or contribute to other fields of historical inquiry, such as social history, political history, the histories of class, economic systems, gender, race, religion, sexual orientation, and so forth? In work that focuses on a specific stream of disability history, such as the history of blind people or the history of public policies regarding disabled veterans, what are its connections to and implications for other streams of disability history? How does our historical research draw upon the more general field of disability studies and what are its implications for disability studies?

The program will include papers on the histories of:

- disabled veterans in post-World War I Britain, Germany, and the United States
- workers with disabilities and the need for a working-class history of disability
- blindness and blind people in colonial Korea, Enlightenment thinking, and the thought of Norbert Elias and Michel Foucault
- people with intellectual disabilities in Norway, the German Democratic Republic, and Scotland
- public policies regarding U.S. immigration, British poor laws, American social welfare
- children, parents, and families in Progressive-era America, mid-20th twentieth-century Britain, the early twentieth-century Netherlands, Early National America, and late twentieth-century Cambodia
- life with a physical disability in nineteenth-century Scotland
- race, slavery, and disability in nineteenth-century America

- disability in the Middle Ages in Europe and the Middle East
- historically involving definitions of disability
- disability and eugenics
- issues and tensions in the interactions of disability history with the histories of African-Americans, women, and medicine
- disability in freak shows and political cartoons
- sources of disability history in biographies, public archives, personal accounts of deaf Arabs, recollections of Independent Living advocates, and a Mad People's Public History Project
- presenting the history of disability in the *Encyclopedia of American Disability History*, as well as in public exhibits and performances

For further information contact:

Paul K. Longmore
Professor of History and
Director, Institute on Disability
San Francisco State University
longmore@sfsu.edu

#### DHA FINALLY HAS PAYPAL!

It is now possible for people to join and renew their DHA membership using PayPal. Instructions for using PayPal to pay memberships fees are posted on our membership page: <a href="http://dha.osu.edu/join.htm">http://dha.osu.edu/join.htm</a>.

### NEWS FROM THE UK AND CANADA

#### NEWS FROM THE UK

(Wendy Gagen and Penny Richards)

In connection with the Disability History Group (contact <a href="wendy.gagen@pms.ac.uk">wendy.gagen@pms.ac.uk</a> for more information), Dr Julie Anderson and Dr Neil Pemberton are organising two workshops in June 2009, looking at issues surrounding blindness and deafness, entitled 'Sound and Vision'. A call for papers will be issued by the end of June 2008. For more information contact Dr Julie Anderson at <a href="mailto:julie.anderson@manchester.ac.uk">julie.anderson@manchester.ac.uk</a>.

The provisional program for "Before Depression: The Representation and Culture of Depression in Britain and Europe, 1660-1800," a conference to be held June 19-21, 2008, at the University of Northumbria at Newcastle and the University of Sutherland, is now available. The majority of titles will be of interest to disability historians, so check out the link: <a href="http://www.beforedepression.com/speakers.htm">http://www.beforedepression.com/speakers.htm</a>.

There's also a component of the project called "18th-Century Blues: Exploring the Melancholy Mind," which focuses on visual representations. The exhibit will be on display at the Shipley Gallery in Gateshead for most of the summer: <a href="http://www.beforedepression.com/Exibition.htm">http://www.beforedepression.com/Exibition.htm</a>.

The Social History of Learning Disability Conference entitled 'Spending Time' will take place on 3<sup>rd</sup> July 2008 at the Open University, hosted by the Faculty of Health and Social Care, and the Social History of Learning Disability Group. The panel of international speakers will be considering such issues as time spent in work, at leisure, and in institutions and will include personal experiences and life histories. For more information and how to register please contact Lesley Henderson at l.g.henderson@open.ac.uk.

Look out for the session on 'Disability and the City', organized by Dr Marie Nelson and Professor Anne Borsay at the next conference of the European Association of Urban History, which is being held in Lyon, France between 27 and 30 August 2008. For further details of the, 9th International Conference on Urban History, 'A Comparative History of European Cities' please see <a href="http://eauh.ish-lyon.cnrs.fr">http://eauh.ish-lyon.cnrs.fr</a>.

The Nottinghamshire Disabled People's Movement and the Holocaust Centre have just held an event entitled, 'Disability and the Holocaust: We Shall Not Forget'. Held on May 11<sup>th</sup>, this event aimed to highlight this rarely discussed public remembrance of the Holocaust. 'The stories of prejudice which arise out of this history are important today, as disabled people were targeted by the Nazis due to their perceptions about the 'genetic impurity' of disabled people. In our contemporary society, the debate about disabled people and their 'genetic rights' is still on-going, especially in the light of advances in genetic and prenatal screening, and the human genome project. Therefore, this event was important in highlighting these current debates which were discussed in terms of equality issues and their historical context.' If you would like more information about this event or to explore the work being done around disability and the Holocaust contact Heather Hollins at hir1@le.ac.uk.

Finally, the latest news from the museums and galleries project, 'Rethinking Disability Representation', funded by the Heritage Lottery Fund and NESTA, with support from the University of Leicester and nine other partner museums, indicates the importance of engaging in cross discipline debate. This is an 'experimental project which is developing new approaches to the interpretation of disability and to the representation of disabled people's lives within museums and galleries'. Evaluation of the ways in which visitors responded and engaged with exhibits and educational sessions is under way. Exciting projects such as Northampton's Museum and Art Galleries' consideration of issues around fashion and footwear and showed the similarities and differences between high fashion and orthopaedic footwear, aimed to make visitors re-engage with these artefacts in a new way. It is great to see dialogue between museum studies, disability studies and historians! More information can be obtained through the project coordinator Debbie Jolly, dj3@leicester.ac.uk.

#### NEWS FROM CANADA

From Canada we have the following news:

"Out from Under: Disability, History and Things to Remember," April 17 to July 13, 2008: <a href="http://www.rom.on.ca/exhibitions/special/out">http://www.rom.on.ca/exhibitions/special/out</a> from under.php.

Out from Under: Disability, History and Things to Remember explores the history of disabled people in Canada. A display of thirteen diverse objects reveals a rich and nuanced story that pays tribute to the resilience, creativity, and the civic and cultural contributions of Canadians with disabilities.

The first of its kind in Canada, this remarkable exhibition was produced in collaboration with students, scholars and alumni from Ryerson University. The origin of Out from Under was a special topic seminar designed to uncover the hidden history of disability in Canada. Students were invited to identify an object representing a particular era or moment in Canadian disability history and explore its significance. The result is a powerful portrait of a community that is vital, dynamic and proud. Out from Under is fully accessible.

"Madness, Citizenship, and Social Justice," June 12-15, 2008, Simon Fraser University, Vancouver, Canada. For more information: http://www.sfu.ca/madcitizenship\_conference/participants.html.

Two medieval history blogs related to disability out of Canada:

The Furnace of Doubt http://eaquaelegit.blogspot.com/

Alison is a Canadian grad student at the University of York

Medieval Cripples, Crazies, and Imbeciles...and a Service Dog?

http://cripples-imbeciles.blogspot.com/

Another Canadian grad student, who's planning to go to the University of York next year

And speaking of blogs, here is an interesting one from the USA by Sarah Heacox at Impossible Universe about Olympians with disabilities in history:

http://impossibleuniverse.blogspot.com/2008/05/other-olympians-with-disabilities.html

#### RECENT WORK IN DISABILITY HISTORY

Simon Hayhoe of the UK has just published God, Money, and Politics: English Attitudes to Blindness and Touch, from Enlightenment to Integration (Information Age Publishing): <a href="http://www.infoagepub.com/products/content/p47dc0a4810c1a.php">http://www.infoagepub.com/products/content/p47dc0a4810c1a.php</a>.

Pieter Verstraete of Belgium sends news of completing his dissertation at Katholieke Universiteit Leuven, "Disability History: A Foucauldian Perspective."

#### PIETER VERSTRAETE, DISABILITY HISTORY: A FOUCAULDIAN PERSPECTIVE.

Doctoral thesis submitted to obtain the degree of Doctor in Educational Sciences, May 2008 Supervisors: Prof. Walter Hellinckx & Prof. Marc Depage

In this doctoral dissertation we have focussed on a domain of study which only recently attracted the attention of history of education scholars: The history of the education and instruction of people with disabilities. On the one hand, we aimed at highlighting the importance of raising methodological issues within this new and challenging field of educational history. On the other, we also wanted to offer the reader some possible histories of disability itself. In this way, the doctoral dissertation can be divided into two parts. The first two chapters can be said to be merely methodological whereas the last three chapters can be said to have a more historical nature.

Within the existing educational historiography the notion of 'disability' receives increasing attention. In line with an Anglo-Saxon research tradition – i.c. the American perspectives on disability history - 'disability' here more and more is considered an effective instrument for historical inquiry into the nature, role and functioning of specific power mechanisms in the history of educational spaces like e.g. the school, the asylum, the institute, the family etc. According to this particular Anglo-Saxon research tradition writing the history of disability is thought to be a decisive element in both the emancipation, liberation of people with disabilities and the realization of an inclusive society. We are convinced that nowadays still many people with disabilities on a regular basis can be encountered in situations of oppression and discrimination. The identification and condemnation of these degrading contexts has to remain an important task for the historian of disability. Nevertheless, the first two chapters reflect critically on the particular way this Anglo-Saxon tradition uses our past in order to liberate and emancipate people with disabilities – and its particular use of concepts like critique, past and history in this endeavour. Here, the work of the French philosopher Michel Foucault functioned as the most importance source of inspiration. On the basis of his ideas about writing a history of the present, his innovative concepts of power and his particular interpretation of the notion 'experience' we have tried – parallel to our critique – to construct an alternative methodological framework for writing the history of the education and instruction of people with a disability. Instead of striving for a radical liberation of persons with a disability, our alternative approach of history – i.c. a dis-abling history – directs the attention of contemporary scholars towards the ideas, values and convictions of the author of a disability history himself. At the heart of this doctoral thesis thus can be found a substitution of a Messianic promise to the other - i.c. the person with a disability - for an unceasing Foucauldian critique of the self and the present.

In the second part of this doctoral thesis we have tried by means of our alternative methodological framework to write a few histories of disabilities ourselves. For this we made extensive use of the several libraries and archives of the Institut National des Jeunes Sourds (Paris), the Association Valentin Haüy (Paris) and the Koninklijk Instituut Spermalie (Bruges). The focus of these histories lies on the representations of and the intercourse with people with mental, auditory and visual disabilities. Successively the role phrenology played in the emergence of educational initi-

atives for people with intellectual disabilities, the transformations in the care for people with visual and auditory disabilities between 1750 and 1860 and finally the problemization and pedagogization of disability towards the end of the eightteenth century was studied. On the one hand, all of these particular histories try to contribute to the existing corpus of disability history by revealing new turns, sources and perspectives. On the other, however, all of these histories also aim at the identification of historical elements which can enlighten critically our current intercourse with people with disabilities.

It is, according to us, exactly by pointing towards those elements which for us became to visible in order to be conceived, that the writing of disability histories can possibly contribute to the emancipation of persons with disabilities. We however do not consider emancipation as the promise of a powerless space in which a new truth can rule accordingly. On the contrary, emancipation here is thought to be a process of change which starts on oneself and creates alternative spaces where new truths, other ways of being and unforeseen possibilities can emerge unboundedly.

Greg Carrier, a budding medievalist and blogger in Canada, reports that there is enough "critical mass" to form a Society for the Study of Disability in the Middle Ages.

## MEDIEVAL DISABILITY STUDIES: AN EMERGING FIELD

by Gregory Carrier (University of Alberta)

Medieval disability studies is a new and emerging field. Much focus has been placed on disability history in the nineteenth and twentieth centuries, with the result that disability before then, particularly in terms of the medieval period, has been relegated to an intellectual backwater of sorts, centered around the idea that medieval ideas of disability saw disability as a manifestation of sin.

With the recent publication of Irina Metzler's *Disability in Medieval Europe*, scholars have begun considering medieval understandings of disability beyond the 'disability as sin' model. This field is so new that scholars who work on medieval disability generally work independently and because they have a personal or academic interest in the subject.

The annual International Congress on Medieval Studies (ICMS) at Western Michigan University in Kalamazoo, Michigan, has benefited medieval disability scholars by bringing them together and allowing them to exchange ideas and discuss the current state of scholarship in the area. At the recent ICMS (8-11 May), there were four sessions on disability (or related to it) in medieval Europe.

#### (Ab)normal Societies: Disability as a Socio-cultural Concept in Medieval Society

This session had two papers, one which discussed definitions of mental illness in Plantagenet England, and the other discussed the socio-cultural framework in which a deaf *converso* nun, Teresa de Cartagena, wrote her memoirs. (Note: A *converso* was a Jew who had converted to the Catholic faith or a Catholic whose Jewish ancestors had converted to Catholicism.) Both papers argued that the act of defining the disabled in terms of their respective subjects relied upon a

flexible and nuanced definition of disability: there was not necessarily a single, unified 'model' or 'theory' that was formulated by theorists (jurists, theologians, and physicians in particular) and ordinary people who cared for or encountered the disabled that translated into a 'set' definition of disability.

# The Scientific Grounding of Medieval Medicine

There was no discussion of disability in this session, but one of the strands of thoughts in medieval disability studies is the idea that rational discussions helped frame and define medieval understandings of disability, and not necessarily just supernatural or divine explanations. The four papers in this session emphasised rational developments in medieval thought by examining specific examples of St John of Beverly's practical medical training and knowledge as outlined in the Venerable Bede's *Ecclesiastical History of the English People*; the relationship between university-trained physicians and empirical medical knowledge; the study of poisons and toxins, and the use of astrological medicine as influenced by Aristotle and Galen in establishing the scientific foundations of medieval prognosis.

#### **Embodied Identities: Disability and Gender in Medieval Literature**

One of the most common misconceptions about medieval disability studies is that there are very few sources either by or about actual disabled people in the medieval period, thus any study of medieval disability must base itself upon literary representations of disability. The paper on aging in *Beowulf* argued that the frequent references to the aging of the characters was used as a cue to the readers of the poem to recall the positive and negative qualities of aging, such as increased wisdom and physical frailty, and to associate those qualities with the characters at specific points during their lives in the poem. In an analysis of the disabling gaze in medieval (French) lyric, it was argued that women projected out of their eyes when they gazed and men received into their eyes when they were gazing: as such, women could 'harm' men by projecting their love and desire, among other emotions, to men. This concept thus both affirmed and disabled women, while also allowing literary writers a safe way of disabling men and their masculinity in late medieval lyric. The final paper discussed the idea of the gaze in relation to the aging body of 'Alisoun' (Alison), the Wife of Bath, from a virile young woman to a stodgy old woman in both Chaucer's *Canterbury Tales* and the 2003 BBC production of the 'Wife of Bath'.

# Disability in the Middle Ages: A Roundtable Discussion

This roundtable brought together six leading medieval disability scholars who discussed their projects and their reflections on the current state and future directions of the field. After brief discussions about wide-ranging topics such as the mentally ill in medieval England to blindness in medieval France to a discussion of the value of a feminist critique of medieval disability studies and a vigorous discussion of how precisely to understand medieval definitions of disability, both in terms of concepts and terminology, the floor was opened to the audience. There was a good discussion about moving disability studies away from the field of literary studies and increasing the scholarship on discussions of lived experience in terms of examining sources that discuss actual disabled people. A second, exploratory, discussion focused on the difficulty of defining the disabled, particularly in terms of looking at the term 'disability' as 'dis-ability' – did medieval people automatically perceive the disabled as being fully incapable of carrying out functions, or were they understood as being dis-abled in that they were able to carry out some

functions and only 'disabled' in others? The roundtable left all participants with a sense that even though medieval disability studies is a new field, it is a field that is extremely full of promise.

A final note: One evening, approximately fifteen scholars interested in medieval disability studies got together for a meeting and decided to form the Society for the Study of Disability in the Middle Ages. The goal of the Society is to "promote an interdisciplinary, scholarly conversation about the history and representation of medieval disabilities."

If anyone would like further information about the Society itself or on how to join, or would like to discuss medieval disability studies at Kalamazoo or in general, please feel free to contact me at <a href="mailto:greg.carrier@gmail.com">greg.carrier@gmail.com</a>. Please include [Medieval disability studies] in the subject line. You may also visit my blog, where I discuss medieval disability issues, at <a href="http://cripples-imbeciles.blogspot.com/">http://cripples-imbeciles.blogspot.com/</a>. Thank you.

#### MEMBER STORIES

Susanne Pohl-Zucker (Germany) and Jagdish (Jags) Chander (India) offer reflections on their work from their respective countries. What makes someone take up research on a subject that constantly needs to be justified and explained? How do they use and stretch existing institutional frameworks to accept not just scholarship but a paradigm that is new and sometimes threatening? And how do they blend scholarship and activism? Together they suggest our international scope and the vastly divergent roads that lead to doing this work.

# DISABILITY HISTORY AS EMPOWERMENT: STRATEGIES FOR PARENTS WITH CHILDREN WITH LEARNING DIFFICULTIES?

Susanne Pohl-Zucker, University Of Tübingen, Germany susanne.pohl-zucker@uni-tuebingen.de

I am based in Germany, currently preparing a research project on historical constructions of Downs Syndrome, and am a recent DHA member. I am a great fan of the newsletter always, but last fall's focus on teaching was especially helpful for me, because I was teaching my course "Introduction to Disability Studies/Disability History" for the first time as a lecturer at the university of Tübingen. I am quite grateful to Cathy Kudlick, Phillip Ferguson and Penny Richards for making their syllabi available on the DHA website. I "borrowed" some of their readings to complement the German material. The students had a great time with the English articles, despite dire warnings from other faculty members about the impossibility of getting them to read in a different language. It was not only the great choice of readings which I found helpful. The comments about teaching the material that accompanied the syllabi in conjunction with the notes on teaching disability history by Phil Ferguson and Kim Nielson provided much food for thought as well. In this short piece, I want to add to these discussions a few observations from my own teaching experience last term.

<sup>&</sup>lt;sup>1</sup> "Teaching Disability History in the Contemporary United States." *The Disability History Association Newsletter*, Fall 2007, Volume 3, Issue 2. p.7-22.

Both Philip Ferguson and Kim Nielson wrote about memorable "moments" in the class room when history and personal experience merged in ways meaningful to class discussion. The common theme was how disability history can be successfully introduced to students as what one might call 'applied history,' as research that enables different perspectives on life outside the class room – without harping too much on the "lessons of history" as Phillip Ferguson put it.<sup>2</sup> Throughout the term, I kept devising strategies to make this happen, some were more successful, some less so. Once it happened quite naturally: one of the things we discussed during the class which had a focus on historical constructions of intellectual disability from the nineteenth century to the present, was the use of intelligence testing in the early twentieth century as an instrument of social control. The unit ended with a German book on the tests used in the 1970s and 1980s, and students were appalled to discover that a lot of the tests from the beginning of the century, with their degrading language for ranking people with learning difficulties, were still in use at that time. Their amazement and their questions led on the spot to an interesting discussion about the very real barrier testing continues to represent today to German parents' wishes for inclusive schooling for their children with learning difficulties. Knowledge of the historical contexts of these tests and the uses they had been put to, offered a critical perspective on the numbers and figures that many contemporary professionals still work with. Here, in Phillip Ferguson's words, disability history allowed students to reconsider "what had previously seemed obiective."3

While I was delighted to see how the students became more and more expert at deconstructing naturalized definitions of disability, this incident made me reflect on my own experience as a mother of a child with learning difficulties in particular and the meaning disability history has for me and might have for other parents in general. I thought for example about the times when I struggle to maintain coherence between different roles – particularly those of activist and mother. Ruptures might occur when a specific challenge leaves me more vulnerable and less ready to fight back than the activist part in me would like. Without turning this piece into "Susanne's story," I want to mention just one example. During a Kindergarten meeting two months ago, I lacked confidence in interactions with parents of typically developed children who are the gatekeepers to a friendship between their children and mine. I acted confused and almost apologetic over those aspects of my child's behaviour which I usually just consider "differently normal" and expressive of his authentic self. In this instant, it was more difficult to be indifferent to the reactions of my surroundings. However, I realized quickly that such confused responses on my part do but confirm negative judgments about "mental retardation," judgements that are reified for example by the very intelligence tests we had discussed in class. From my regular engagement with parent support groups. I know that such inadequate responses are often enough a part of daily life. They may happen when the fear which makes you most vulnerable - that your child may experience rejection – endangers a self-confident stance against the pressures of the medical model and existing prejudices. Disability History helps me navigate such pit falls and bring my actions as "mother" and "activist" into coherence, because I can understand these actions and those of the people around me in a historical context of marginalization of people with learning difficulties.

<sup>&</sup>lt;sup>2</sup> Phillip Ferguson, "A Selective Historical Glimpse at How American Society Has Tried to Educate, Rehabilitate, or otherwise Intervene in the Lives of Disabled Children and Adults, and Their Families, and How Some of Them Have Always Resisted." Ibid, p. 20.

<sup>&</sup>lt;sup>3</sup> Ibid.

I also find that historical research has positive effects on efforts to resist those bureaucratic decisions which narrow the possibilities of children with learning difficulties. Lately, the support group I am a part of was asked to write an appeal against a decision of the local social services. A significant part of a child's early intervention program had been curtailed. The reason given was that the child was already six years old, and that it was not to be expected that she would make further significant progress because of the severe "mental retardation" caused by Downs-Syndrome. Our anger about this kind of genetic determinism and a priori denial of an openended future, a denial which interprets children's every move as "a reflection of syndrome," as Dan Goodley so aptly puts it, was fueled by bits of historical knowledge.<sup>4</sup> I had recently read an article by C.F. Goodey on the origin of definitions of intellectual disability in John Locke's writing, an article which I like especially because it is written to familiarize professionals with the historical contingency of such definitions.<sup>5</sup> While we resisted quoting John Locke against the government official, we stressed this contingency as a background to our insistence on a social model of disability which leaves no room for narrow definitions of a child's potential. It may not have been the brief historical allusion that won the appeal, but our discussion of history helped us focus and sharpen our arguments – in sum strengthened our self-assurance.

Such self-assurance is important when interacting with professionals. Let me stay with the example of intelligence testing. These tests are a standard part of the application procedure when parents wish inclusive schooling for their children with learning difficulties. Often, parents become more hesitant about this wish when the tests result in a recommendation to send the child to a special school. It could be liberating for parents to know more about the historical contingency of these intelligence tests. Perhaps such knowledge would make it less difficult for some to muster the courage to abandon a traditional automatism which associates certain scores with certain schools and certain pedagogical strategies. The race to enforce a perceived "normalcy," which often leads to anxious comparisons and strained relationships between parents and children, could be left behind. Awareness of the historical strategies of marginalization of people with learning difficulties might help parents a) to avoid the traps of the medical model and b) take some pressure off themselves and off their children in order to experience more freely that spontaneous, unjudging delight in a different self.

When the class discussion about the history of intelligence tests triggered these kinds of thoughts in me, I thought – why not inject a dose of history into parent training workshops? And to take this further, why not involve the students? Next time, I am teaching the class, I hope to invite local representatives of activist groups. Perhaps these sessions could conclude with a workshop. Students and activists could develop suggestions on how to go about communicating parts of history that could be used strategically in interactions with professionals and bureaucrats. All this could be taken further even. Our group is currently putting together a presentation on inclusion for high school students. We could include a section on Disability History...There are many different possibilities. It is of course naïve to think that bits of historical knowledge alone can smooth the stony road towards inclusion for children with learning difficulties. Lots of parents

© The Disability History Association, 2008

<sup>&</sup>lt;sup>4</sup> Dan Goodley, "Learning Difficulties, the Social Model of Disability and Impairment: challenging epistemologies." *Disability and Society*, Vol. 16, No. 2, 2001, pp. 224.

<sup>&</sup>lt;sup>5</sup> C.F. Goodey, What is Developmental Disability? The Origin and Nature of Our Conceptual Models." *Journal on Developmental Disabilities*, Volume 8, No.2, p. 1-8.

might consider history exotic, too academic, or simply too far removed from their current struggles. However, it would be worth a try to see if it might not be empowering to some. At the very least, I found that teaching disability history not only teaches students something, it also made me consider and process my own actions and reactions in ways meaningful to my efforts to empower my son.

# HISTORY AND DISABILITY IN INDIA

Jagdish Chander

Jagdish ("Jags") Chander is a Senior Lecturer (Associate Professor) in the Department of Political Science, Hindu College, University of Delhi, India and doctoral candidate in the Disability Studies program at Syracuse University, USA. He is currently completing his dissertation on the self-advocacy movement of the blind in India and a biography of Lal Advani, a leading disability rights advocate and father of rehabilitation services in the 20th century. His recent publications include "The Role of Residential Schools in Shaping the Nature of The Advocacy Movement of The Blind In India" and a chapter co-authored with Susan L. Gabel, "Inclusion in Indian Education," both in Susan L. Gabel and Scott Danforth, Disability Studies and Education (Peter Lang Publishing, 2008). His presentations at various international conferences, academic interest in disability rights issues, and passion for being an activist in the disability rights movement, make him one of the most distinguished people working in the field of history of disability in India from a Disability Studies perspective. Below he describes how he came to do this work and provides an overview of recent scholarship. He can be reached by email at: jagdish100@hotmail.com

The publication of noted American journalist Joseph P. Shapiro's, 1993 book *No Pity: People with Disabilities Forging a New Civil Rights Movement* aroused great interest from disability rights activists and scholars of Disability Studies in the United States and India. Shortly after its publication, I participated in a discussion held through video conferencing between some scholars and activists from both countries. In addition to Shapiro, they included Judy Heumman and Justin Dart, both prominent disability rights activists from the United States, and some leading people involved in disability issues in Delhi in March of 1994.

Soon after that discussion, the Dehli-based group followed up by forming a cross-disability coalition to advocate for the passage of comprehensive legislation ensuring the rights of disabled people in India. The organization was named Disability Rights Group (DRG). A core committee was formed that consisted of people with different categories of disabilities: three blind people, four physically-impaired people, and one person who was a scholar interested in people with cognitive disabilities. It was not a highly comprehensive group, but it was a start. Prior to the formation of the DRG, the only organized self-advocacy movement was that of the blind. Being blind since the age of six, I was educated in the two residential schools in Delhi which were the hub of this movement when I was a student there during the 1980s.

My involvement in the DRG gave me an opportunity to become part of the struggle for the enactment of the first comprehensive disability law in India and kindled my interest in disability history. Having completed my B.A. and Master's along with an M.Phil. in Political Science from

the University of Delhi, I was heavily inclined toward conducting research on rights issues. My background enabled me to remain in touch with the literature on various kinds of social movements in India, like the dalit movement (movement of the oppressed classes/castes), the communist movement led by the Marxist groups, the socialist movement led by followers of Gandhian ideology such as Jay Prakash Narayan and Ram Manohar Lohia, and also to some extent the emerging feminist movement. However, there was hardly any documentation of the disability rights movement available in the 1990s in India.

While struggling with the dilemma of pursuing doctoral study in this area, I participated in an International Congress of Asian and North African Studies held in the fall of 2000 in Montreal, Canada. Although I did not meet anyone engaged in academic discourse on disability issues from a non-medical model approach at that Congress, during my stay I had an opportunity to interact with some Canadian scholars of Disability Studies from York and Ryerson Universities. Through them, I learned about a Disability Studies conference to be held in Washington D.C. in the third week of October sponsored by the National Institute on Disability, Rehabilitation and Research (NIDRR). It was at this conference that I learned about the Disability Studies program at Syracuse University. Greatly excited, I visited Syracuse in the last week of October. During interactions with the students and faculty at SU, I realized that I found what I was looking for: a program which would enable me to conduct research on disability with a disability rights perspective. I began in the fall semester of 2001.

During my coursework at Syracuse, I conducted six interviews with activists of the National Federation of the Blind (NFB) and the American Council of the Blind (ACB), the two leading advocacy organizations in the United States. I also spent about a month collecting data at the Professional Development and Research Institute on Blindness (PDRIB), a partnership between NFB and Louisiana Tech University located in Ruston, Louisiana. I was fascinated by the intellectual and political movement of the NFB, which challenged the construction of blindness by vehemently championing blind people to become self-advocates, rather than being on the receiving end to get whatever was offered by the mostly sighted professionals heading various service agencies for the blind.

My three years of coursework at Syracuse University, enriched me with a theoretical understanding of a Disability Studies perspective. Having acquired a reasonable knowledge about the philosophy and accomplishments of the advocacy movement of the blind in the U.S. and India, as well as having been part of the broader disability rights movement through my involvement in DRG during my early adulthood, I was now ready to venture on to pursue my old goal of documenting the disability rights movement in my country.

Initially I wanted to pursue a project that would bring together information from the advocacy movements of the blind in the U.S and India, with that for the broader disability rights movement in India in the 1990s. Considering the fact that the disability rights movement is more recent in my country, it would have been easier to document because it was well-covered by the print and electronic media. However, the advocacy movement of the blind that originated in the 1970s required serious scholarly attention. To be sure, there had been some media coverage of incidents like the lathi charge upon blind protesters in March 1980. This standard practice of police quelling rioters with sticks scandalized the public that viewed disabled people only as those to be pi-

tied. It became clear to me that there was an important story to be told, one that I could and should document through oral histories. It is likely that research will be undertaken in India on the broader disability rights movement as disability becomes a social and political issue at the national level and a subject of academic interest in the decades to come. But this can not be understood without documenting the history of the blind self-advocacy movement.

Prior to the formation of the DRG in March 1994, the advocacy organization which made its presence felt at the national level was the NFB of India, founded in 1970, an organization inspired by but not directly related to the organization of the same name in the United States. In the 1980s NFB spearheaded a radical blindness movement by resorting to methods such as picketing, rallies, hunger strikes, demonstrations, and the like. Therefore, when it came to advocacy for rights of the disabled, it was basically the advocacy movement of the blind led by the NFB for over two decades. In demanding their own rights, the blind often spoke for those of other disabled people as well. These efforts culminated in India's Persons with Disabilities Act (equal opportunities, protection of rights and full participation), known as the PWD Act of 1995. This initiated a new phase in the history of disability in India, something that needs to be explored and carefully documented, as the following overview of the existing literature in the field of disability should make clear.

Apart from a few exceptional books written from a Disability Studies perspective, most of the Indian literature falls in the category of the medical model. There has been no identifiable work mentioning the advocacy movement of the blind in India. For that matter, little work exists on our disability rights movement apart from Meenu Bhambhani's 2004 unpublished master's thesis at the University of Illinois at Chicago. And she doesn't discuss the role of the blind.

The only publication by an American scholar that I could identify which touches upon the issue of the disability rights movement in India is part of a chapter in James Charlton's, *Nothing about Us without Us* published a decade ago. By focusing exclusively on the National Association for the Blind (NAB) which he incorrectly portrayed as the largest and most powerful disability rights group, he failed to mention the country's true advocacy organization, the NFB. The fact is, for most of its existence, NAB has been a service agency in the area of blindness, and until very recently it vehemently opposed the disability rights approach adopted by organizations like the NFB.

One of the most important earlier publications in the area of disability which ventures beyond the medical model is Usha Bhatt's, *The Physically Handicapped in India* published in 1963 which remains a highly cited reference on disability in India even now. However, Bhatt's approach was more sociological and based on moral considerations rather than a disability rights perspective. She explores the changing attitudes of society toward disability by tracing them to the scriptures in India and to western philosophy starting from Aristotle's views on disability. Bhatt elaborates the karma model (actions of past lives making an influence on the present life) in the context of disability and explains the reasons for the lack of development of a medical model of disability in India. She argues that while the break-up of the extended family and two world wars had a tremendous impact on social attitudes toward disability in the west, the same wasn't true for India. Because it remained relatively unaffected by the world wars in the last century, the disabled segment of the society did not receive attention from policy makers and planners. As a result,

social attitudes toward disability continued to be highly influenced by the moral or charitable approach arising out of the traditional Hindu notions of karma and dharma (religious duty).

Neither of the two important publications of the 1980s, Chaturvedi (1981) and Mani (1988), mention the advocacy movement of the blind, its accomplishments, and its approach. A similar line approach was adopted by T.N. Kitchlu (Kitchlu, 1991) in relation to welfare services for the blind in India in the second half of the 20<sup>th</sup> century. While Mani and Chaturvedi dealt with disability issues from a policy angle in a broad way, Kitchlu claimed to analyze the educational and employment measures adopted for the blind by the welfare State of India. In these three books, the clear message sent to readers was that disabled people had received all the benefits accorded to them as a part of the welfare philosophy of the Indian State, not as a result of the struggle carried out by them for their rights.

The decade of the 1990s witnessed progress in recognition of the importance of the advocacy approach. The passage of the ADA and the movement preceding it in the United States, the origin of a broader disability rights movement in India in the first half of the 1990s, the passage of the PWD Act of 1995, and the growing disability studies literature in the West gradually started to influence writing about disability in India. As a result, scholars such as Asha Hans and Annie Patri (2003) and Anita Ghai (2003) have started to adopt a disability studies approach. However, these are the only two identifiable publications in India that can be put in the category of disability studies so far. Much work remains to be done!

#### References

- Bhambhani, M. (2004). "From Charity to Self-advocacy: the Emergence of Disability Rights Movement in India. Unpublished M.A. Thesis, University of Illinois at Chicago.
- Baquer, A. (1994). *Disabled, disability, and disabilism*. New Delhi: Voluntary Health Association of India.
- Baquer, A., and Sharma, A. (1997). *Disability: Challenges vs. responses*. New Delhi, India: Concerned Action Now.
- Bhatt, Usha. 1963. *The physically handicapped in India*. Bombay: Popular Book Depot.
- Charlton, J. I. (1998). *Nothing about us without us: Disability, oppression and empowerment.* Berkley: University of California Press.
- Chander, J., and Baquer, A. (2005) *Lal Advani: The torch bearer*. Delhi: Indian Association for Special Education and Rehabilitation.
- Chaturvedi, T. N. (Ed.). *Administration for the disabled: Policy and organizational issues*. New Delhi: Indian Institute of Public Administration.
- Gabel, S. L., & Danforth, S. (2008). *Disability and the politics of education: An international reader*. New York: Peter Lang.
- Ghai, A. (2003). *Embodied form: Issues of disabled women*. New Delhi, India: Shakti Publications.
- Hans, A., and Patri, A. (Eds.). (2003). *Women, disability, and identity*. New Delhi, India: Sage Publications.
- Kitchlu, T. N. (Ed.). (1991). *A century of blind welfare in India*. Delhi, India: Penman Publishers.

- Mani, D. R. (1988). *The physically handicapped in India: Policy and programmes*. Delhi, India: Ashish Publishing House.
- Pandey, R. S., & Advani, L. (1996). *Perspectives on disability and rehabilitation*. Delhi: Vikas Publishing House.
- Shapiro, J. P. (1993). *No pity: People with disabilities forging a new civil rights movement*. New York: Times Books (Random House).
- Scotch, R. K. (1984). From good will to civil rights: Transforming federal disability policy. Philadelphia, PA: Temple University Press.