

Spring, 2009 DHA NEWSLETTER
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In this issue we have a number of terrific, thoughtful features including member profiles by Alice Wexler from the USA and Iain Hutchison from Scotland, as well as the first of a two-part interview with leading disability history scholar Henri-Jacques Stiker. We also have a report on the Disability History Conference held at San Francisco State University in August and a description of the holdings in disability history at the US National Library of Medicine in Bethesda, Maryland. And we have information about new books, upcoming conferences, and blogs of interest to historians of disability. Please keep your suggestions and other contributions coming!

MESSAGE FROM THE PRESIDENT

November 2008- March 2009

I am pleased to announce the success of two important initiatives that give the DHA greater clout and legitimacy. In January 2009 the American Historical Association granted us affiliate status. Affiliation offers us a broad network within the AHA and will enable us to collaborate with other groups and share information about our field to a much wider audience. Gaining affiliated status also enables us—through the AHA--to contribute new ideas for publishing and doing history, as well as to sponsor joint sessions at the annual meeting. Such an alliance also adds credibility to our growing field and organization.

Second, the United States Internal Revenue Service (IRS) has granted the DHA the status of a nonprofit tax-exempt corporation (501c3). This means that members can deduct their dues and any other contributions to our organization when paying taxes in April. It also means that we're now free to fundraise during the most serious financial crisis since the Great Depression. Still, the victory tastes sweet. After more than two years of work that involved dozens of people we can now begin to think about funding book and article prizes, graduate student fellowships, and other exciting initiatives to advance the field. I'm also heartened by a recent article in *The New York Times* that suggested that some charitable giving actually increased during the 1930s.

Such a historical moment has caused me to reflect upon the overused sayings "thinking outside the box" and the alleged Chinese curse "may you live in interesting times." Both apply to my two-week stay at Columbia University's Mailman School of Public Health as a visiting scholar on a "diversity" fellowship in September 2008. Indeed, it was unprecedented for a top-ranked university to approach *History* as a form of diversity. Seriously, I can't think of many institutions that have considered disability alongside race and gender as bringing a form of intellectual richness to an already vibrant cultural fabric. Here I must thank Corinne Kirchner, president of the Society for Disability Studies (SDS) back in its early days in the late 1980s, now in what she

calls “rewirement” teaching at Columbia, who crafted a convincing application for the school’s diversity initiative.

During my visit I presented a couple of talks, met with various administrators, and sparred with engaged colleagues in the program in “History, Ethics, and Public Health.” Formed in the social history of medicine, these scholars working on projects such as occupational health, illness narratives, and responses to AIDS do work that overlaps with disability in fascinating ways. But they hadn’t thought much about a disability perspective, or even that they - like so many folks in the history of medicine - could be disability historians. And until recently, I hadn’t thought about my own relationship to the history of medicine, even though my dissertation and first book were about cholera epidemics. Engaging with historians in a public health environment as opposed to that of a history department has helped me ask what it means to cast oneself as one kind of scholar versus another. Are there merely differences of emphasis or genuine methodological and paradigmatic divides? Is it possible to embrace both fields?

I experienced the “interesting times” aspect of my stay by being in New York as the financial situation was unraveling. Breathing in the city’s increasingly apocalyptic mood, I thought about how future historians would look back on attempts such as ours to launch a new scholarly field during flush economic times, only to confront times of increasing instability and dread. Was it possible that our own intellectual risk taking-had parallels with the speculators on Wall Street? Perhaps all of us striving to bring greater diversity to the academy and to society in general would wake up one day to discover that we had been pampered and indulged during a more prosperous era. Such fears take on particularly disturbing connotations when considering the history of disability where, in times of crisis people who are seen as physically or mentally anomalous are among the first to be cast aside - or worse - as “useless mouths.” Approached from this dire perspective, it isn’t hard to imagine efforts such as ours being viewed with increasing skepticism and parsimony in attempts to preserve “core” programs and initiatives.

Of course there is another way of looking at the situation. Just maybe a return to more sobering economic times will call into question the frenetic pace and the hedonism of perfection that have gotten out of control in the past two decades. Just maybe, the average citizen of the United States and western Europe will have a deeper first-hand understanding of what it means to live in a world without a sense of entitlement. And just maybe - with adequate prompting from people like members of the DHA - this would bring a greater appreciation for what disability has to offer. I’m not resorting to trite pronouncements about deeper understandings of humanity. Rather, I’m thinking about lessons in pragmatism and resourcefulness in the face of unpredictability that have long been overlooked as one of the true hallmarks of living with a disability. These efforts permeate the work of both disabled and nondisabled scholars alike as we strive to promote the field. Even as we challenge prevailing ideas and assumptions of the academic mainstream, we must devise creative ways of working within that system to make a case for what we do and why. Perhaps as more people experience adversity, a disability perspective will have greater appeal. After all, hardship can invite everyone to expand notions of social justice in both scholarship and teaching.

In solidarity,
Cathy Kudlick (cjkudlick@ucdavis.edu)
DHA President

NEWS OF THE DHA BOARD

Special thanks to Audra Jennings and Robyn Fishman who provided the DHA their valuable services in its early years. We wish both of you the best of luck! In October, the board elected replacements.

Secretary: Heather Munro Prescott (prescott@ccsu.edu)

Heather Munro Prescott received her undergraduate degree in Comparative Religion, summa cum laude, from the University of Vermont in 1984. She received her M.A. (1989) and Ph.D. (1994) in Science & Technology Studies from Cornell University. She joined the faculty at CCSU in that year, where she has served as co-coordinator of Women's Studies and as department chair. Her teaching and research interests include recent U.S. history, U.S. women's history, and the history of medicine and public health. Now that she has completed her second book, *Student Bodies: The Impact of Student Health on American Society and Medicine* (Michigan, 2007), she begins a new project on the history of emergency contraception. She has held a number of fellowships, including one from the National Endowment for the Humanities and a National Institutes of Health Publication Grant from the National Library of Medicine. Her first book, *A Doctor of Their Own: The History of Adolescent Medicine*, (Harvard, 1998) received the Will Solimine Award of Excellence in Medical Communication from the New England Chapter, American Medical Writers Association.

Graduate Representative: Lindsey Parker (parker.619@osu.edu)

Lindsey Parker, received her M.A. in Deaf Studies from Gallaudet University in 2007. She is currently a Ph.D. student in the Department of History at The Ohio State University. She has published articles on gender and deaf identity and has contributed entries to the forthcoming *Encyclopedia of American Disability History*. Her current research interests include gender, disability, and citizenship in modern U.S. history.

Iain Hutchison (iain@keapub.fsnet.co.uk) joined the Board as our UK representative in February. Iain graduated with First Class Honours at the University of Strathclyde, Scotland, in 2000 - his dissertation was on 'Child Disability in Scotland c.1872-1914'. He completed his PhD at the University of Strathclyde in 2004 with a thesis on 'The experience and representation of disability in nineteenth-century Scotland'. His book, *A History of Disability in nineteenth-century Scotland*, was published in 2007. Journal articles include “...and rimmain yoor obbeddeend omble zervand”: the invented spelling system of William Baillie of Dunain

(1789-1869)' with Nigel Fabb, Professor of Literary Linguistics, University of Strathclyde – Transactions of the Philological Society – 2005, Vol 103:3; and 'Oralism – a sign of the times? The contest for deaf communication in late nineteenth century Scotland' - European History Review – 2007, Vol:14:4. He is a Teaching Fellow in History at the University of Stirling; and is Development Officer for the Economic and Social History Society of Scotland www.eshss.gcal.ac.uk. Be sure to read his member profile of how he got into disability later in the newsletter.

Phil Ferguson has replaced Sandy Suffian as treasurer, and will now handle matters related to membership: pferguson@chapman.edu

OPPORTUNITIES FOR PARTICIPATION

The DHA is particularly interested in hearing from members who would like to get involved in helping to raise money for prizes, scholarships, and launching a scholarly journal. We realize that academics recoil from such initiatives, but it is essential for taking the organization to the next level and really promoting a field we care about. If you have ideas, including experience with similarly small organizations that managed to grow, please contact Cathy Kudlick at cjkudlick@ucdavis.edu.

DHA & THE AMERICAN HISTORICAL ASSOCIATION

The Disability History Association continues to work with the largest organization of professional historians in the world. Our aim is to draw attention to disability as a valuable area of historical scholarship and teaching, at the same time that we try to make the profession more welcoming of people with disabilities. We believe that the two goals are inseparable; excellent scholarship creates a greater awareness and appreciation for diverse scholars, while these scholars help to advance the historical discipline in a variety of areas, not all of them necessarily related to disability.

The DHA was active at the January 2009 annual meeting in New York and hopes for an even stronger turn-out next January in San Diego. To inspire people, note that our sister organization, the Modern Language Association had THIRTEEN panels devoted to disability at their recent meeting in San Francisco. (Okay, historians had ONE full panel at AHA, but there were also a number of papers related to disability in various sessions throughout the conference, a good sign.)

Now that the DHA is an Affiliated Society with AHA, we have additional possibilities (including a later submissions deadline) for raising the profile of work in disability history at the annual meeting. If you are interested in proposing a paper or panel related to a topic in disability history, please submit the following to Cathy Kudlick (cjkudlick@ucdavis.edu) by April 15, 2009:

- Session title (of no more than 20 words)
- Session abstract (up to 500 words)
- Paper or presentation titles (except for "panel" round tables that list only name and affiliation)
- Abstract or description for each presentation (up to 300 words)
- Mailing and e-mail address for each participant (especially important for non-members)
- Chair (required) and commentator (optional) for the session
- Audiovisual needs, if any

AHA TASK FORCE ON DISABILITY ISSUES

The first meeting of the Task Force on Disability Issues will take place at the AHA. Paul Longmore and Sandy Suffian will represent the DHA, along with three members of the AHA's Professional Division: David Weber, Leisa Meyer, and David Ulrich. If you have any suggestions or concerns that you think the DHA should bring to the table, please contact Sandy Suffian: sufians@uic.edu

DHA at OAH (Organization of American Historians, March 26-28, 2009 in Seattle)

A number of disability historians will be presenting work and will be getting together in Seattle. Watch H-Disability for opportunities to meet with other DHA members at the meeting, or contact Kim Nielsen at: nielsenk@uwgb.edu

Penny Richards posts the following information of interest to us:
 OAH conference details are here:
<http://www.oah.org/meetings/2009/program/index.html>

Kerri A. Inglis (University of Hawai'i, Hilo): "Patients or Prisoners? Identity, Resistance, and Resilience in the Lives of Leprosy Patients in Hawai'i (3/26, "Native Diasporas" session)

Jeffrey Womack (University of Houston): "Mutants in the Desert: The Impact of Nuclear Imagery on Science Fiction Films" (3/27, "Doomsday Scenarios" session)

PANEL: RETHINKING PSYCHOHISTORY (3/28)

Chair: Bertram Wyatt-Brown (U of Florida)

Michael Fellman (Simon Fraser U): "Rethinking Psycho History: The Benefits and Challenges of a Mental Illness Framework in Writing History"

Paula Kamen (Northwestern U): "Finding Iris Chang: Challenges of Biography with the Bipolar Diagnosis"

S. Nassir Ghaemi (Tufts Medical Center): "Madness and Leadership"

Comment: Kim Niesen (U of Wisconsin Green Bay) and Bertram Wyatt Brown

PANEL: STATE OF THE FIELD: DISABILITY HISTORY (3/28)

Chair: Vicki Ruiz (UC-Irvine)

Susan Burch (National Museum of American History)

Sara Robinson (Ohio State U)

Richard K. Scotch (University of Texas, Dallas)

REPORT ON THE DISABILITY HISTORY CONFERENCE, SAN FRANCISCO STATE
UNIVERSITY, AUGUST 2008

Report on Disability History Conference at San Francisco State University

July 31-August 3, 2008

By Paul K. Longmore (longmore@sfsu.edu)

Professor of History, San Francisco State University

The academic field of disability history is burgeoning. It has developed to the point that in mid-summer 2008 some five dozen scholars gathered at San Francisco State University for a four-day conference entitled "Disability History: Theory and Practice." This conference, convened by San Francisco State's Institute on disability, was co-sponsored by the Disability History Association and the Disability History Group. Most of the scholars who attended are historians, but there was valuable representation from a variety of other disciplines: communication studies, literary studies, performance studies, philosophy, physical therapy, sociology, special education, women's studies, and, of course, disability studies. Participants came from around the globe. The largest representation was from the United States, but attendees also travel from Canada, the United Kingdom, the Netherlands, Germany, Norway, Finland, Japan, and South Korea.

The expansion of disability history is obvious if we just glance at the myriad topics scholars have been researching as represented by the papers presented at the conference. Many focused on American subjects. Presenters examined disability in Early National U.S. families and antebellum U.S. slavery. They looked at workers with disabilities in the late nineteenth and early twentieth centuries: "crippled" newsboys and injured railroad men and other laborers who continued working in one way or another after acquiring their disabilities. Other scholars probed representations of disability in freak shows and political cartoons, Progressive Era social welfare policies and professional practices, and ideologies about parenting children with cognitive disabilities in the era of World War I, raising blind children just after World War II, and regulating "delinquent" teenage girls in the mid-twentieth century.

In addition, a large proportion of the papers addressed topics from many other places in the world. One paper examined blind workers in nineteenth and twentieth century Korea. Others reported on people with physical disabilities in nineteenth-century Scotland, education of developmentally disabled children in Norway and East Germany, mothers of mentally retarded

children in the Netherlands, representations of abnormality in Zionist and Palestinian propaganda in Mandate-era Palestine, and disabled World War I veterans in Britain and Germany. Two scholars reached back in time to consider disability in medieval Europe, while another reported on early modern European ideas about whiteness and albinism, and still another discussed constructions of blindness in the Enlightenment. A number of papers took up methodological and theoretical issues in doing disability history, and one entire panel was devoted to the question that confronted the editors of the forthcoming *Encyclopedia of American Disability History*.

The conferees also engaged in practical planning to develop the field of disability history. Half a dozen planning groups began to strategize work in half a dozen areas of importance to historians and other scholars working in this field and to the advancement of the field itself. Those six groups addressed: career development for junior historians working in disability history; archival materials and research resources; development of a high school curriculum on disability history; planning for an international journal of disability history; institutional development and fundraising; professional issues for historians with disabilities.

In a closing plenary session, many of the participants expressed the hope that this conference will be followed not only by other such conferences, but by continuing efforts to develop the field of disability history among professional historians and other scholars.

BOOKS & BLOGS

ANNOUNCING THE PUBLICATION OF PAUL LOMBARDO'S NEW BOOK ON BUCK V. BELL

Three Generations, No Imbeciles: Eugenics, the Supreme Court and Buck v. Bell (Johns Hopkins University Press, 2008)

***Three Generations, No Imbeciles* is a chronicle of the 1927 Supreme Court case Buck v. Bell, which approved laws allowing states to perform surgery in order to prevent “feebleminded and socially inadequate” people from having children. The Buck case was the first and only time in Supreme Court history that an intrusive medical procedure - involuntary sterilization - was endorsed as a tool of government eugenic policy. It is doubly notorious for the court's decision, written by renowned Justice Oliver Wendell Holmes Jr. Holmes' declaration that “Three generations of imbeciles are enough” led to lifelong infamy for Carrie Buck and her family.**

Paul A. Lombardo's startling narrative is the only fully documented account of the Buck case ever written. He was the last person to interview Carrie Buck before she died, and the book incorporates material he discovered over more than twenty-five years of research. Items such as Carrie Buck's medical records, the honor roll grade book of her daughter,

Vivian, private correspondence of the lawyer who was named to represent her, and the only existing photos of all three generations of the Buck family support the conclusion that the Buck case was a fraud, initiated to hide the shame of a poor girl, pregnant after she had been raped.

Although the Buck decision set the stage for more than sixty thousand operations in the United States and was cited at the Nuremberg trials in defense of Nazi sterilization experiments, it has never been overturned. This book tracks the career of Buck in American memory, as a potent symbol of government control of reproduction and a troubling precedent in the human genome era.

Paul A. Lombardo, PhD, JD is Professor of Law at the Center for Law, Health, & Society at the Georgia State University College of Law.

Table of Contents

Introduction

Prologue: The Expert Witness

Chapter 1. Problem Families

Chapter 2. Sex and Surgery

Chapter 3. The Pedigree Factory

Chapter 4. Studying Sterilization

Chapter 5. The Mallory Case

Chapter 6. Laughlin's Book

Chapter 7. A Virginia Sterilization Law

Chapter 8. Choosing Carrie Buck

Chapter 9. Carrie Buck versus Dr. Priddy

Chapter 10. Defenseless

Chapter 11. On Appeal: Buck v. Bell

Chapter 12. In the Supreme Court

Chapter 13. Reactions and Repercussions

Chapter 14. After the Supreme Court

Chapter 15. Sterilizing Germans

Chapter 16. Skinner v. Oklahoma

Chapter 17. Buck, at Nuremberg and After

Chapter 18. Rediscovering Buck

Epilogue: Reconsidering Buck

Acknowledgments

Appendix A. The Supreme Court opinion in Buck v. Bell, by Justice Oliver Wendell Holmes Jr.

Appendix B. Virginia Eugenical Sterilization Act, 1924

Appendix C. Laws and Sterilizations by State

Notes

A Note on Sources
Index

ANNOUNCING THE SECOND EDITION OF 'JAMES CASTLE: HIS LIFE AND ART'
EXPANDS ON STORY OF MISUNDERSTOOD IDAHO ARTIST (from a press release)

The second edition of *James Castle: His Life and Art* by Boise State University professor Tom Trusky and first published in 2004, has been released by the Idaho Center for the Book. It contains rare documents and photographs, exclusive interviews with Castle's family, childhood friends and contemporary art and medical experts. The new edition features two new chapters as well as 200 black-and-white and color images and maps. The book has been revised and updated, including the notes and bibliography.

The book has been called “the definitive critical biography of Castle,” the native Idaho artist who died in Boise in 1977. Labeled for his entire life as deaf, mute, illiterate and mentally challenged, Castle is now thought to have been autistic. Born in 1899 in Garden Valley, he was the fifth of seven children. He never learned to speak, had a limited ability to read and write and he seemingly refused to be taught to sign. His primary form of communication was the thousands of books, drawings and illustrations he produced during his lifetime. Houses, domestic scenes, family members and friends were endlessly rendered in what some have termed a primitive “folk art” style from crude tools and supplies — ink made from soot and saliva, pens fashioned from twigs or sticks and canvases scavenged from scrap paper, cardboard, books and the many catalogs that flowed through his parents’ general store and post office. Even when family, friends, curators and artists purchased paints and brushes for him, late in his career, he preferred to make his own tools. Castle devoted himself to making art for more than 60 years. Although briefly “discovered” in the 1960s, he was largely unrecognized during his lifetime. He left behind more than 20,000 artworks.

The book is available at the Boise State Bookstore and Amazon.com.

PENNY RICHARDS FOUND THESE RELEVANT BLOGS:

<http://hmprescott.wordpress.com/2008/09/26/scotland-and-sshm-finally/>

Heather Munro Prescott's report from the SSHM conference in Glasgow

<http://crip-power.com/2008/10/08/its-already-october/>

Blogger makes a logo and link list for Disability History Month

THE NATIONAL LIBRARY OF MEDICINE (USA) – HOLDINGS IN DISABILITY
HISTORY

Disability History Resources at the National Library of Medicine (www.nlm.nih.gov)
Manon Parry

The library is open to the public 8.30am to 5pm Monday to Friday, and 8.30am to 2pm on Saturdays. Bring a photo i.d. to access campus, and for new patrons, to receive a library card on your first visit. Much of the information below can be found through the library's online catalog, LocatorPlus, and finding aids for manuscript collections are available on site. Most will be uploaded to the online catalog in the next few months. Contact the author: Manon Parry, National Library of Medicine, 8600 Rockville Pike, BG 38 Rm 1E-21, Bethesda, MD20894, parrym@mail.nlm.nih.gov (301.594.1948).

The National Library of Medicine on the outskirts of Washington, DC, houses one of the world's largest collections of history of medicine materials. Originally located in the office of the Surgeon General of the Army, the collection is particularly rich in resources on the history of military medicine, including images, publications and papers pertaining to the American Civil War, the Russo-Japanese War of 1904-1905, and World Wars I and II. Manuscript holdings include the papers of military hospitals and army surgeons based in various locations. The Prints and Photographs Collection, of approximately 100,000 images dating from the fifteenth through to the twenty-first centuries, includes many taken by Civil War photographer Mathew Brady. The rehabilitation of veterans is also well documented in photographs of soldiers with artificial limbs undertaking physical therapy as well as images of interactions between patients and physicians, nurses, or physical or occupational therapists.

Public health initiatives constitute another major area of disability study represented in the collections, with more than 20,000 postcards and around 12,000 posters dating from the mid-nineteenth century to the present across a broad array of topics. As well as campaigns against tuberculosis in France ca. 1917-1942 and posters from the Red Cross Christmas Seal campaigns 1919-1938, more contemporary materials are also featured, including an extensive number of HIV/AIDS posters produced by activist groups as well as government health agencies, from various countries. The library also recently acquired and catalogued the papers of former surgeon general C. Everett Koop and houses the National Commission on Acquired Immune Deficiency Syndrome records. There are also a number of manuscript collections relating to tuberculosis and poliomyelitis therapy and the polio vaccine.

A repository of medical research, the library has gathered journals, monographs, and the personal papers of physicians and biomedical scientists since the nineteenth century. As in other medical history collections, most materials reflect the perspectives of medical practitioners and offer few glimpses into the views of the people with disabilities. The library does hold a number of case studies that might be useful for this purpose, however, such as James Wardrop's *History of James Mitchell, A Boy Born Blind and Deaf, With an Account of the Operation Performed for the Recovery of His Sight* (1813). In recent decades, collecting policies have also been expanded to encompass print and non-print materials that document the history of medicine, health, and disease in all time periods and cultures. Of particular interest to disability studies scholars, this

also means a broader interpretation of health-related topics to include learning disabilities, stammering and other speech issues, and so-called “sexual disabilities” or sexual dysfunction and infertility.

The library has gathered some of the most important primary sources in the history of deafness and blindness, such as *Institutions des Sourds et Muets* (1774) by sign language pioneer Charles-Michel de L’Epee, Alexander Graham Bell’s collection of lectures to promote the teaching of the deaf, *The Mechanism of Speech* (1907), and William Moon’s *Light for the Blind* (1873). Other printed holdings include pamphlets and reports of international congresses, and a large number of annual reports from various institutions including the Alabama Institute for the Deaf and Dumb and the Blind (1871-1886) and the American Asylum, at Hartford, for the Education and Instruction of the Deaf and Dumb (1819-1893).

Major manuscript collections include the records of medical organizations such as the Association of Military Surgeons of the United States, the American Association for the Surgery of Trauma, and the American Burn Association. The database “Images in the History of Medicine” contains several thousand group portraits showing medical societies and conventions. Although most association records pertain to medical organizations founded by physicians, some document the activities of patient advocacy groups, such as the papers of Jacob M. Ulmer, a lawyer who developed cataracts in the 1940s. Ulmer cofounded the National Foundation for Eye Research in 1949, and lobbied Congress to create an institute on blindness at the National Institutes of Health.

The library also holds the papers of Thomas Francis "Mike" Gorman, who was appointed executive director of the lobby group the National Committee Against Mental Illness in 1953. These holdings are part of a large selection of materials on mental health which includes the papers of Dr. Lawrence Kolb, an international expert in the study of psychiatry and narcotics in the 1930s, appointed Assistant Surgeon General in 1942. His work, along with that of Dr. Thomas Parran, led to the creation of the National Institute for Mental Health in 1946. Other collections in this area include the papers of Bertram S. Brown, Director of the National Institute of Mental Health under the successive administrations of Presidents John F. Kennedy, Lyndon B. Johnson, and Richard M. Nixon, and the National Institute of Mental Health oral history collection, 1975-1978.

The records of the female ward and annual reports of the Commerce Hospital and Lunatic Asylum of Ohio from 1840s-1860s are among nineteenth-century resources pertaining to the history of mental illness. Also relevant are the papers of Shobal Vail Clevenger, a pathologist at the Insane Asylum of Cook County at Dunning, Illinois. Clevenger agitated to end mistreatment and neglect of patients, but attempts on his life persuaded him to resign his position in 1884. There are also more than 700 images depicting the history of mental illness from the sixteenth century through to the twentieth century, including caricatures of the treatment of patients. Photographs include interior and exterior images of mental hospitals and asylums in the United States, Italy, England, and Paris, and devices and procedures. Medical instruments including

orthopedic apparatus are extensively documented in the images collection.

Finally, the library's film holdings on the subject consist mostly of sound films from the 1960s on. A large proportion of these depict rehabilitation programs for the treatment of infantile paralysis, spinal cord injuries, amputations, head injuries, and following cardiac arrest or stroke. Others focus on daily life, such as the 1965 government production Co-twin Study, A Day in the Life of a Blind Child and Her Sighted Twin, or disability rights or history, including The Blind, An Emerging Minority (1974) by the National federation of the Blind and Through Deaf Eyes, A Photographic History of an American University (2007) by Gallaudet University Press.

MEMBER PROFILES

IAIN HUTCHISON

What got YOU into disability history...?
© Iain Hutchison (iain@keapub.fsnet.co.uk)

“Do you have a...?”, or “Is someone in your family dis...?” are the usual unfinished questions that are prompted when I tell people that I research disability history. My standard response is: “No, I am not disabled. But I ride a motorcycle so I'm working on it.”

My own interest developed by an unscheduled encounter with a grave headstone. I was about to embark upon my undergraduate dissertation for which I was going to examine lead mining in the Southern Uplands of Scotland. Then I had some overseas visitors for whom I had to take on the role of tour guide. One bright Sunday morning, I took them to the old heart of Glasgow where we visited Provand's Lordship, the city's oldest house, and the St Mungo Museum of Religious Life and Art. Next stop was the Cathedral, but we found that a service was in progress and we had half an hour to kill in order not to intrude upon the congregation during its spiritual deliberations. One of my friends said, ‘Can we look at the cemetery while we are waiting?’ While the Cathedral has a fascinating ancient cemetery, she was beckoning beyond to the Glasgow Necropolis, a burial ground built on a hill where the style and location of the tombs reflects the nineteenth-century social hierarchy and composition of the city. It was opened in 1832 as a garden cemetery, intended to emulate the dash and style of Père la Chaise in Paris, and is surmounted by an austere and chastising statue of the religious reformer, John Knox (c. 1510-1572). The higher that visitors climb, the more ornate and extravagant are the nineteenth-century headstones that assault their visual senses.

However, it was a plain slab at the bottom of the site that caught my attention. This modest slab had a list of names that ran down its length and into the soil. There were more names on the reverse side. How many interments were in this small lair? Closer inspection showed that it belonged to East Park Home and the grave's first interments began in 1875. I knew that this was

a home for crippled and infirm children, but that the Home had recorded the deaths of young inmates, who would mostly have been consigned to paupers' graves had they died in their own homes, intrigued me. I found that records existed in several locations, including some that were uncatalogued and were unearthed by accident. My lead-mining project was abandoned. I was off on a new tack.

East Park Home was opened in the aftermath of compulsory education being introduced in Scotland in 1872. The Education Act of that year gave birth to ranks of attendance officers who sought out children who were not going to school. Their thoroughness revealed housebound children, many with debilitating tubercular conditions, in numbers that had not previously been appreciated. An Association was set up in Glasgow to aid some of these children in their homes, but the severity of many cases encountered was such that a residential home was deemed necessary and East Park Home opened in 1874.

As a result of this stroll with my guests, East Park Home played a crucial part in my undergraduate dissertation which focused on child disability in Scotland c.1872-1914. My investigations, however, focused on a broad range of impairments and societal responses during the period between the introduction of compulsory education and the onset of the Great War. PhD study broadened my research to encapsulate the whole nineteenth century and also adult experience. Rather than specialising on one type of impairment, comparison between different disabling conditions, periods and localities are all part of my interest. Like many of us working in the disability history field, I quickly became frustrated by what institutional sources did not willingly tell us and my work has increasingly prioritised hearing the voices of people with disabilities above the voices of those who intervened in their lives.

Currently, my teaching is on modules in Scottish, British and European history that cover the broad sweep of dynamics of everyday life in the late modern period. Until such times as I get a focussed history of disability module off the ground, I emphasise that disability was a pervasive feature of everyday life during my period - the nineteenth century, something which Penny Richards and I brought to the fore through our panel presentations at the 'Disability History: Theory and Practice' conference in San Francisco in August. I emphasise that disability history is not an obscure specialism, but mainstream to our understanding of history.

But I've written enough for this occasion. Now I'm off out for a spin on my motorbike! How did YOU get into disability history?

Iain Hutchison is the author of *A History of Disability in Nineteenth-Century Scotland* (Lewiston, Edwin Mellen Press, 2007)

ALICE WEXLER

My Three Feet Dancing; or How I Came to Disability History
Alice Wexler, Research Scholar, UCLA Center for the Study of Women

I am tempted to say that I came to disability studies and disability history because I was instantly persuaded by the amazing books, articles, academic papers, and friends I encountered, starting in the 1990s. But in truth, my journey into disability history was a far more gradual process. While any account of intellectual change probably reveals more about the moment when it is written than about the events of the past, I nonetheless offer one possible narrative of my own venture into the land of disability history, where I have been exploring the territory, if not quite building a home.

As a historian who began graduate work in Latin American history in the late 1960s, taught the history of women in the US in the 1970s, and wrote a biography of the anarchist Emma Goldman in the 1980s, I was familiar both with comparative approaches to history and, more important, with feminist arguments about the importance of gender, race and class as inextricably linked categories of historical analysis. Disability as an analytical category made sense to me as a historian even if I did not always understand the radical ways that disability activists and scholars were starting to use it.

However the more immediate reason for my attraction to disability studies, and ultimately, to disability history, was my personal experience with Huntington's disease (HD), popularly called St. Vitus's dance, and once known within medicine as Huntington's chorea on account of the involuntary dancelike movements (chorea) that are its most characteristic symptom. I should note here that Huntington's differs markedly from those conditions that have been central to the disability rights movement and to disability studies. Unlike impairments such as blindness, deafness, or anatomical difference, Huntington's progresses inexorably toward total physical incapacity, dementia and death over ten to twenty years. Most people in the later stages of HD cannot operate a wheelchair, speak intelligibly, communicate via a computer, or use the assistive devices available to people with other kinds of impairments. Even in the early stages they often suffer psychiatric difficulties and loss of cognitive capacity leading to loss of employment and even conflicts with the law. Huntington's is also one of a small group of severe conditions that is inherited as an autosomal (non-sex-linked) dominant disorder, meaning that each child of an affected parent runs a 50% risk of inheriting the variant gene. For many of those living with Huntington's, the knowledge that they may have unwittingly passed it on to their children and grandchildren produces almost unbearable guilt.

The symptoms are dramatic. Along with chorea, most people suffer personality changes, emotional disturbance, and cognitive decline. Typically starting in a person's thirties or forties (though it can begin much earlier or later), this disease, which has been reported in all races and ethnicities, affects some 30,000 people in the US, with about 150,000 more at 50% risk.ⁱ

For such a devastating condition, then, a medical model certainly seems appropriate. I would say that all members of the HD community want to see this disease wiped out, unlike members of the disability rights community who often feel that their disabled situation offers a valuable perspective from which to view the world. Many members of the HD community also use their

situation in creative ways, but given the choice, no one that I know from a family with Huntington's, including my own, would choose this option for themselves or their children. Many feel that those who would choose suicide over living into the last, late stages of this disease ought to have this option.

And yet, over the past several years, as I came to know more families with the disease and attended more Huntington's meetings and workshops, I found myself struck by the extent to which members of affected families talked as much about the social and cultural dimensions of their suffering as about the more narrowly medical ones. Especially in the early stages, people living with Huntington's often seemed to feel more handicapped by social discrimination, isolation, and lack of modest assistance than by their choreic movements, a situation very much like that of people with other impairments. Almost all members of families with Huntington's, affected and unaffected alike, suffered from stigmatization and secrecy, the taboo against speaking of the disease even inside the family; from ill-informed and even prejudiced health professionals; being told they should not marry or have children; insurance discrimination. Those living with the disease often experienced the embarrassment of being stared at in public, or asked to leave a restaurant on account of disruptive movements. They suffered the loneliness of being unable to work and remaining at home with nothing to do, without personal assistance and usually the expectation that care would be performed by family members as unpaid labor. Almost always there was the near impossibility of finding appropriate long-term care for those in the advanced stages of the disease. Those who reported the least painful experiences with Huntington's often stressed their social support and access to services.ⁱⁱ

In addition, because of its direct inheritance pattern, Huntington's seemed to stamp a kind of social identity on entire families, even though only a few members might actually have symptoms at any one time. HD advocates as well as health professionals referred to "Huntington's families," as if HD gave a special identity to everyone in that kinship, affected and unaffected alike, recalling the early twentieth-century eugenic discourse surrounding "defective," "degenerate," and "unfit" families.

In the summer of 1968, I learned for the first time that I belonged to one of those families. I learned that my fifty-three-year-old mother now had the dreaded symptoms that had killed her father, grandfather, and all of her brothers in their fifties, that my sister and I were at 50% risk of inheriting the same illness, and that if we did, we could pass on this disease to any children we might have.

Soon after my mother's diagnosis and the revelation of the family secret, my father plunged into the newly emerging world of Huntington's disease advocacy, followed a few years later by my sister, who became a Huntington's researcher herself. Excited by the recombinant DNA revolution of the 1970s and the advances in gene mapping of the 1980s, they, along with many others, were swept up in the optimism and excitement of "cutting edge science." Science was going to find "the cure" and not waste time and energy on halfway, palliative efforts. As a historian, I was attuned to thinking about the social dimensions of this scientific discourse, but I

too got caught up in the romance of the gene. I wrote a book, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (University of California Press, 1995), weaving together an account of recent genetic research on Huntington's with a more personal narrative about the familial impact of the disease.

Still, the process of researching and writing *Mapping Fate*, and especially the conversations and conferences that followed, opened up for me many questions being raised by disability studies scholars and activists. In some respects, I think I learned more after completing *Mapping Fate* than I did while writing it, at conferences and in conversations with other scholars and HD activists.ⁱⁱⁱ Many of the conferences I was invited to participate in addressed issues of disability in one way or another, often in relation to gender and to genetics--the focus of *Mapping Fate*--as seen through the lens of the social and cultural studies of science, technology, and medicine. Scholars such as Deborah Heath, Helen Longino, Jonathon Marks, Paul Miller, Paul Rabinow, Rayna Rapp, Tom Shakespeare, and Susan Squier opened my eyes to new questions about the cultural and social meanings of genes, genetics, and eugenics in relation to definitions of self and identity that were sometimes at odds with the perspectives prevailing within the Huntington's disease advocacy world. For instance, while voluntary personal choice emerged as the mantra within the HD community in the 1980s with respect to predictive genetic testing, the anthropologists and sociologists at these meetings took a more critical view of the rhetoric of "choice," emphasizing its economic and social limitations as well as its gendered and racial dimensions. And while people at risk for HD generally lauded PGD (Preimplantation Genetic Diagnosis) when it became available, seeing it as a way to have children who did not carry the variant gene even if they did themselves, scholars at these conferences raised questions about the cultural implications of technologies such as PGD, not only for people with disabilities but also for those who can know they carry genes for diseases that may emerge only late in life. These scholars pointed out that the new genetic technologies often had unanticipated consequences and complications--getting pregnant with *in vitro* fertilization, required for PGD, is not always possible, even for those who can afford its high cost--and were actually creating new categories of disability, such as the person who has tested positive for a disease that she will develop later in life (like Huntington's) but as yet has no symptoms. *Mapping Fate* did address some of these issues, but as I look back on it now, I accepted too willingly the idea that having Huntington's--or finding out you were going to get it--was the worst catastrophe in the world, without considering more critically whether or when that was really the case, what made it so, and what might mitigate this outcome.

As a historian, of course, I also found myself thinking about the relevance of these perspectives for understanding the past. Eugenics, which haunted all these discussions, became another vehicle in which I traveled into the land of disability history. From the moment we found out about Huntington's in our family, I had wondered about my mother's secrecy. Why hadn't she told us her father died from Huntington's chorea, as it was then called? I can't recall just when I began to learn about the eugenics movement, but I know that as I learned more about it, I realized that my grandfather's death in 1929 coincided with the height of the organized eugenics movement in the United States, and that my mother had also come of age at that time, in the

1920s and 1930s. She had studied biology as an undergraduate at Hunter College, in New York, in the early 1930s, and had earned an M.A. in zoology soon after at Columbia University. Geneticists at that time studied *drosophila*; in the 1930s human genetics meant *eugenics*, which was considered a legitimate science despite growing criticisms from some geneticists. It occurred to me that the eugenics movement might explain a lot about my mother's secrecy. As Stephen Selden's book *Inheriting Shame* indicates, she almost certainly would have encountered eugenic ideas in her biology textbooks and college courses. ^{iv} Undoubtedly she was familiar with the writing of the eminent biologist Charles B. Davenport, a leading North American eugenicist who had argued in favor of sterilizing people like her. As we know now, eugenics was a vastly popular social and scientific movement in the twentieth century U.S., and Huntington's disease, unlike "feble-mindedness," actually fit the Mendelian paradigm of inheritance embraced by many eugenicists.

My mother had never spoken to me about eugenics. But increasingly her shame and silence about Huntington's made sense in light of the eugenic milieu in which she grew up. Even critics of eugenics might have considered a woman like her a fitting subject for sterilization. I wanted to know more about how eugenic discourse affected my family, and other families as well. These were precisely the kind of questions that, by the mid-1990s, disability scholars as well as disability activists had begun to address.

Against this background, in the late 1990s I began the research that ended up as a book, *The Woman who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (Yale University Press, 2008). I organized this book as three distinct but overlapping narratives, one of which dealt with the impact of early twentieth century eugenics on U.S. families associated with the disease, and another which explored how disparate behaviors came to be conceptualized, in the mid-nineteenth century, as a specific hereditary disease. But the dimension that most captured my imagination was the challenge of trying to recapture the lives of people who had lived and died with Huntington's (or what was often called St. Vitus's dance or the magrums) in the late eighteenth and nineteenth centuries. I became obsessed with the desire to tell their stories, perhaps because they always appeared as shadows or ghosts haunting the medical literature on Huntington's. George Huntington had based his famous 1872 account of "hereditary chorea" on several families in East Hampton, New York, where he grew up, yet for reasons of confidentiality and medical convention, he did not name them, and left no published records of their identities. Despite the sparse evidence, I wanted to give them an historical presence and make them part of the narrative of Huntington's disease. (Ironically, this project was possible in part because of a eugenics field study that documented some of these old families.)

In fact, my research suggested that in nineteenth-century East Hampton, the local families associated with St. Vitus's dance were integrated and accepted in their community, even while their "weakness" was feared and "the subject was avoided by most people as distasteful." Although families with Huntington's appear to have been ostracized and shunned in certain other towns, in East Hampton that did not seem to be the case. East Hampton suggested that even so dramatic and severe a disease as Huntington's might be understood variously in different

historical contexts, and that it did not necessarily lead to rejection. As I came to this conclusion, I saw parallels with Nora Groce's study of hereditary deafness on Martha's Vineyard, and began to think more about the relevance of a disability studies perspective for understanding Huntington's disease, and more broadly, the uses of Huntington's for conceptualizing disability. ^v

In short, Huntington's disease gave me a ground, a vantage point from which to enter the wider world of disability studies and disability history. In this sense, the experience of living within a Huntington's disease family and having a personal connection to what Paul Miller has called "the trauma of eugenics" became the starting point for exploring larger questions about how we define what is "normal" and "abnormal," and how such categories are used for political and cultural ends. Even if I remain personally committed to supporting efforts to find a cure for Huntington's, that commitment does not preclude a commitment to the broader goals of the disability rights movement, and to exploring the construction of disability historically within different temporal and cultural settings. Indeed, what is so exciting to me about disability studies is the radical challenge it poses to many of my own long-held assumptions about embodiment, suffering, and a meaningful life, in the past and in the present.

Having arrived at this point, how, then, do I look back upon my previous work that did not address either Huntington's disease or disability? Actually, I am surprised to see certain continuities between my recent projects and this earlier work. My first published articles in the 1970s argued that the predominantly white US soldiers and travelers to a multiracial Cuba in the nineteenth century constructed the Cubans according to racist stereotypes back home, in ways that flattered their own self-images and helped create subordinate subjects of imperialism. ^{vi} The biography of the anarchist Emma Goldman that I wrote in the 1980s traced the life of a woman whose entire project was to agitate on behalf of the excluded and oppressed, and to work for a society without hierarchies based on economic, racial, gendered or sexual differences. ^{vii} These projects, it seems to me now, resonate with my later work on Huntington's, since they all, in one way or another, address the question of how dominant groups represented subordinate or excluded or stigmatized Others, and the ways in which these Others countered such representations: questions that also resonate with the concerns of disability studies and history today.

But I do not wish to impose too unifying a pattern on this disparate work. I do wish to note that while belonging to a family with Huntington's no doubt closed off some possibilities in my life, it also opened up others, in particular an embodied appreciation for the ways in which disability scholars today are reconceptualizing the meanings of bodies and embodiment, in the past well as in the present. Huntington's provided a jumping off point for a journey on which I have only just begun.

I think of myself now as having one foot in the social and cultural history of medicine, another foot in disability studies and history, and a third foot – or whatever it may be--in the Huntington's disease advocacy community, where I am active as a board member of the Hereditary Disease Foundation, an organization--headed by my sister Nancy Wexler--whose mission is finding a

cure for the dancing disease of Huntington's. While each of my three feet often dances off in a direction of its own, throwing me off balance and even knocking me down from time to time, I enjoy the challenges and pleasures of this dance, and the new music and the movement that it demands.

CATHY KUDLICK INTERVIEWS HENRI-JACQUES STIKER – PART ONE

Henri-Jacques Stiker is the first scholar to attempt a global, sweeping history of disability from Greek times to the present. Trained in philosophy and anthropology, he has been the leading figure in disability studies in France since the publication of his important book *Corps infirmes sociétés : Essais d'anthropologie historique* in 1982. English-speaking readers know the second edition of this book as *History of Disability* published by University of Michigan in 1999. Among the dozen books he has authored, co-authored, and edited are studies of art, public policy, and theory, all related to disability, and most of the work grounded in history. Now retired after teaching at a number of universities in and around Paris, he epitomizes the French academic, full of enthusiasm and energy, trained in several languages and conversant with scholars in a variety of disciplines. He is warm and open to every kind of idea. He speaks slowly and deliberately, a fact that sometimes makes it easy to forget just how well he blends theoretical abstraction and practical knowledge of policy.

Kudlick interviewed him at his home on the edge of the Montparnasse neighborhood in Paris in February 2008. What follows is her transcription and translation of their ninety-minute talk. In Part I they discuss how he came to disability history and the changes he made to the third edition of *Corps infirmes*. Part II, which covers Stiker's thoughts about disability history as a field and his current research will appear in the Spring 2009 DHA Newsletter.

CJK: Of course the first question is how you came to this subject, why you chose to write on the history of disability.

HJS: I studied philosophy, and here in France studies in philosophy end up being about other things. There are of course the big ideas and thinkers, and I don't compare myself to them. But I went into the humanities. It happened that I met a person with a serious disability who convinced me to study it, and so I invested my qualities as an anthropologist and historian into the area of disability.

CJK: But how did this person convince you?

HJS: Well, some encounters are decisive, while others are less so. This one was decisive because this person had something powerful, a real sense of drive, of conviction that well, it just seduced me. So I entered into the field of disability, even though I'm not disabled myself, and didn't

have any real experience with it.

CJK: So there's nobody in your family with a disability?

HJS: No, no one. I came to it through a chance meeting with someone.

CJK: That's really interesting, because usually there's someone - a relative or someone close who influences us, if we aren't disabled ourselves.

HJS: Well, I did have my training in philosophy, and as a result, what interested me most was historical anthropology, more than History with a capital H like trained historians do. I'm interested in grand representations, systems of thought, the structures beyond history, more than pure erudition. Out of this I attempted something that I think most historians would find ambitious, even a little crazy - to trace the grand systems of western thought from Greek times to the present. For a true historian this would be an impossible move.

CJK: Yes, I take your point.

HJS: At the same time, because there was nothing at all in this field of history, it seemed worthwhile to traverse the centuries before entering with precision into this or that moment of history.

CJK: So you met this person who inspired you. But where did you turn for intellectual inspiration? What books did you read? Did you plunge right into "primary sources" or did you look to theory?

HJS: In France there was a pathbreaking book, that of Michel Foucault on madness. Foucault had shown that by going to a document you could analyze a whole epistemology, a whole period, etc. I did a little like he did, and asked myself "What did the Greeks think of disability, of infirmity, so I'll go look at Greek texts." I plunged into Greek literature, and reinterpreted Oedipus. And there were a certain number of books, like that of Marie Delcourt who was a historian of Greece who wrote in the interwar years. In fact she wrote on this question of teratology, these monsters, prodigies. So there were texts that she discovered, and offered a number of her own hypotheses, which meant that I didn't start from zero. Afterwards, I continued by asking "What did the Jews think?" because of course the sources of western thought are part Greco-Latin and part Hebrew. I dove into the Bible to see what it said about all this. After that I got interested in the Christian Middle Ages. Here there were very, very few works on disability, but through texts on poverty I found references, so I went to the texts, to see the books written by historians. Basically, I tried to have the most documentation possible for each of the periods, like an anthropologist working on history - he doesn't work directly on the population, he can't interview them!

CJK: Did you know from the start that you were going to write a grand work like *History of*

Disability?

HJS: Pretty early on, I envisioned this big historical sweep, telling myself “oh well, I’ll try this synthetic approach that would take up certain periods and develop a certain number of points.” After all, because I was the first one, I figured that others would come along later. This was in the 1970s, early 1980s, and there really was nothing else in [disability] history. The only thing out there was some narrowly focused work about the history of special education at the end of the nineteenth and early twentieth century written not by trained historians but by people who taught in specialized institutions and who were looking back on this history. Because there was a lot of ideology in the 1960s and 70s when everyone was critiquing the basis of society, people studying this history were mostly looking at it in terms of what it revealed about militancy.

CJK: Were you aware of the work being done in the Anglo-Saxon countries at this time?

HJS: No, not at all because in Europe, and in France in particular, these movements like Independent Living or DPI [Disabled Peoples International] and all these that would give rise to Disability Studies were practically unknown. The first time I really discovered any of this was in 1988, pretty late, was at a lecture at the Conservatoire national des Arts et Métiers in Paris where Ed Roberts, one of the founders, had been invited. It was talking with him that I discovered, late, this whole movement of Disability Studies.

CJK: And what did you think of Ed Roberts?

HJS: A meeting like that is really striking! Striking, first because a man like that has such power of conviction, such experience, such abilities as an orator. It was weird [folklorique], if I dare say so. I met him at the airport, and he got off with four or five people, his wheelchair weighed 500 kilos. I met him with other people and we took him to a hotel near Les Halles.

CJK: Was it accessible?

HJS: Oh yes, of course! There weren’t many [accessible hotels], but we found one of the few.

CJK: So you started to realize that there was this movement happening in the US.

HJS: I was aware that something was happening in northern Europe. I’d taken trips to England, to Holland, etc. But the French were largely oblivious to everything that would give rise to DPI and other movements in the US until later.

CJK: Let’s return to your book *A History of Disability*. Was it well-received? Did you have trouble finding a publisher at the time [the early 1980s]?

HJS: No, I didn’t have any trouble, in that I found a publisher, Aubier-Montagne, which no longer exists because it was bought by Flammarion that was a publisher in the humanities. They did something that nobody does anymore, which is that they wanted to have a collection, a base

of books on different subjects, even if such and such book didn't sell very well. It didn't matter because the important thing was to have a good list. Madame Aubier, the director, was very sensitive to what was new, to subjects that hadn't been covered a lot, because that's what she saw as distinctive about her list.

CJK: And then it came out, there were reviews....

HJS: Well, it was read and received in the field of disability.

CJK: And elsewhere? Nothing from historians or philosophers?

HJS: No, very little [in the way of actual reviews]. But when it first came out, it did get attention in important places like *le Monde des Livres* and in history journals. I had an impressive file of press clippings. A certain number of people discovered it, including [top historians of France] Michelle Perrot, maybe Alain Corbin, and Georges Vigarello. So in fact in the areas of history and anthropology a certain number of people paid a little attention to it. But it didn't make a huge splash in humanities scholarship. Still, because it was a serious book it made its way into a second edition, and now it is part of bibliographies, not just in the field of disability, but also in histories that in one way or another touch upon disability. It followed a modest, but constant path.

CJK: Has it been translated? In English of course. But other languages?

HJS: Yes, [the second edition is translated] into English, but no other languages. When I went to the Society for Disability Studies I met David Mitchell, who was president at the time, and he had it translated. [for the Corporealities series he edits for University of Michigan Press].

CJK: Let's talk about the newest edition.

HJS: Yes, in 2005 there was a third edition, after the second one in 1997.

CJK: Was there a big difference between editions?

HJS: There was a much bigger difference between the second and third editions than between the first and the second ones, which is too bad for the English-reading public!

CJK: Can you describe these differences?

HJS: Over the past few years I've been looking into the pertinence of a certain number of sweeping visions, maybe a better term would be grand theories, about disability. In the new chapter I added I discussed what boils down to five basic theories of disability. I don't mean the formal international classifications, which are really just descriptions. I mean actual theories. For me, a theory is a hypothesis, a point of view, that unifies, tries to explain a whole, like there

are overarching theories of mathematics or physics, etc, which try to explain a number of phenomena.

First, there are sociological theories, the principal ones being Goffman's ideas about stigma, where he tried to explain many phenomena related to people with disabilities. So here you have a powerful, all-encompassing sociological theory.

Next, we have something less powerful, but also an all-encompassing theme, the cultural, communitarian explanation, stemming from the Deaf community. Here of course the United States was a pioneer, with the affirmation of Deafness as a culture because it has its own language, because there are traditions, because there's a group of people who come together to think, to act from a certain [shared] perspective.

CJK: And what was the key work or works?

HJS: The most important of course is Harlan Lane's *When the Mind Hears* [first English edition in 1984] which was translated into French [in 1991]. I believe this is the key reference for my approach because it's a historical work that tries to present deafness as a cultural experience. It really struck me that certain works of disability studies attempted to show that there's a disability culture. So here there seems to be at least the germ of a bigger theory that tries to bring together a large number of facts having to do with disability.

The third existing theory comes from the British from Leeds, represented principally at the time by Colin Barnes, Mark Priestly, and Tom Shakespeare, eventually torn apart from within by a number of polemics. They had a view that was largely sociological and decidedly Marxist, in that what counted was social factors such as material and financial conditions, which leads to considering disabled people as an oppressed group. It's the theory of oppression. In the end it's still quite different from that of DPI.

CJK: And the vision of Disabled People's International is what?

HJS: It's influenced by disability studies, but also more by sociological ideas from the European continent linked to Marxism. Taken together these strands present what might be considered a unifying theory about disability: the idea which tries to show that barriers imposed by society has been the main, even the only, handicapping factor. Michael Oliver said something like "once you remove social barriers, there won't be anymore handicaps, that there won't even be any more infirmity." This is a pretty strong point of view!

CJK: Are these British texts translated into French?

HJS: No. One has to read them in English, along with the journal *Disability and Society*. In France, apart from me and a few other researchers, this work isn't known at all.

The fourth theory, which I think is the most relevant is that of Robert Murphy, that of liminality. Maybe this theory is better known in France and in Europe than in the United States.

CJK: Murphy's book *The Body Silent* [1987] was better known right after it came out. But now more people are starting to read it again.

HJS: What really impressed me in this book was his type of self-reflective anthropology. It was anthropology with links to his own experiences, kind of like when Freud pioneered the idea of doing analysis of himself. Murphy engaged in auto-anthropology, which I thought was fabulous. And his ideas of liminality have a theoretical importance that is quite powerful.

CJK: And Murphy is translated into French?

HJS: Yes he was [in 1990]. But nobody noticed his work at first. We have to thank a certain scholar Marcel Calvez, who is a professor of sociology at the University of Rennes and someone well connected in the English-speaking world. I think he was a personal friend of Mary Douglas. He was the one who first drew attention to Murphy. I even directed a thesis on the idea of liminality.

The fifth theory isn't by an American or even a Brit, but instead it's from Freud. He understood that through the notion of "the uncanny," the fact of disability, of infirmity, brings us back to our own self image, that it's a broken mirror of ourselves, and that this explains why we're always distressed, and that we approach [disabled people] with avoidance, overprotection . . . Briefly put, through the uncanny, we have another theory for understanding disability.

Thus, we have a number of different powerful theoretical possibilities. So I said to myself, all of these [five theories] have some truth to them, that each one has different strengths and limits.

CJK: Why did you decide to add this as a chapter, as opposed to writing a whole different book or even an article?

HJS: I wanted to have something different to add to the new edition. I could have done a whole book, the subject would have merited its own book. But I settled for just a chapter.

CJK: You have plenty of books out anyway, right? How many now?

HJS: I have only five single-authored books. Co-authored and edited, maybe ten or twelve. You know, I could have done a whole other book [on the theories]. But I wanted to get it out fairly quickly, without having to wait.

CK: And the new edition, is it selling well?

HJS: Oh yes! The second edition was sold out, and now there's the third one. It's a book that's

being read. It is a useful scholarly book [un vrai livre de travail].

CK: It's a foundational book.

HJS: I'd like to say that more than anything, one wants to introduce a new idea among all these others, but I didn't create a new idea or story to attract attention. I did want to bring together and explain several of these theories. I think in terms of anthropology and sociology, Murphy is the most relevant today. But Murphy doesn't explain why people get left in a state of liminality. He says, "here we are in this state of liminality, we'll never again find ourselves in the situation we were before, nor in the one that we would have wanted, we're stuck at a border, at a threshold, and it's impassable, that apparently society or others can't get us across to full integration." So I asked myself, but why? At the very least, Freud's response offers some insight into why we leave disabled people in this liminal state: because they frighten us, there's always a fear, a discomfort, always something that makes it so that we feel too close.

But today, socially we can't say that they don't have a right to exist either. Just the opposite. We speak of integration, acceptance, participation, everything. So Murphy is right to speak in terms of liminality. But that doesn't explain anything until we consider this famous "broken mirror" that shows how the Other provides us with an image of ourselves that we have difficulty accepting. And we need to understand that this division exists for the disabled and nondisabled. At the heart of the disabled world there's this same phenomenon, for example people with physical disabilities are uncomfortable around those with mental illnesses, etc. It's obvious, but still needs to be pointed out because of prevailing beliefs that there's a difference between disabled and nondisabled people.

So again I wondered, where does this disconcerting strangeness come from? I hypothesized that this Different Other, different in his body, in his 'conformity,' was in fact our double. So I went to see what a number of theorists who write about doubles had to say, notably Otto Rank, a disciple of Freud's who worked on the idea of doubles in literature. I believed I could argue that disability [l'infirmite] could be the image we have of our double, something which is part of us that we don't like, but at the same time *is* us. One can't separate oneself from one's double. One doesn't walk on or even separate oneself from one's shadow. But at the same time, one doesn't necessarily like one's shadow. So we're in an ambivalent relationship with ourselves. Thus I advanced the idea that the phenomenon of the double brings us back to the idea of the uncanny being able to explain the position of liminality. I was at a crossroads between the mental and the social, and there I found the major anthropologist of our times, Marcel Mauss, who always emphasized that social meaning came from both the individual and the collectivity where one finds anthropological meaning. You can't be just a psychologist or just a sociologist. Instead we must blend the two areas where we find ourselves in the realm of total society, a phenomenon having multiple aspects, multiple elements.

This was how I synthesized all that I found interesting in theories of disability.

CK: And in the rest of the third edition, were there any other changes?

HJS: No, not much else. I expanded upon a few areas that I found to be too short in the first edition. In the section on Ancient Greece and myths, I added commentary on a number of myths, including a discussion on blindness and the myth of Tiresias, the blind god who changed sexes, so striking in Greek mythology. I also developed a discussion of the grand sociological tendencies when one looks at social groups where at bottom there's a temptation to see them in one of two extremes. In one, at the level of groups or nations is the idea of assimilation. That means that anyone who is different or foreign must assimilate, conform to what is the rules of the group. He must fit into the group and not show his difference. This is a tendency heavily associated with republics of the west, such as that of France. They want citizens who fully conform. Through schooling they get citizens who mold themselves into the group.

In the United States by contrast, the tendency is one of differentiation. Everyone is different. You can push a theory of differentiation until it becomes one of differentialism. Then you're only in a kind of dust, a mosaic no longer in the form of a society. And with disability we're in a similar situation. Either you become like me, you try to be able-bodied, etc. so that people forget your differences. Or you're so different that oh well, you should just stay in your own corner. There are only these two tendencies.

So I developed all this a bit more in the new edition, how if groups don't work within this equilibrium, one heads toward rejection under the pretext of respecting difference or one heads toward restraint through normalization, also under the pretext of making difference disappear.

CJK: Will this third edition be translated into English?

HJS: I don't think so, because I haven't been in contact with University of Michigan Press to make it happen. But I wouldn't be against it!

Endnotes for Wexler Piece

ⁱ See Gillian Bates, Peter Harper and Leslie Jones, eds., *Huntington's Disease*, 3rd ed. (Oxford University Press, 2002).

ⁱⁱ At an international meeting of patient advocacy groups a few years ago, I was startled to hear a woman from Belgium--a country with excellent health and social services--whose sister, brother, and father had had Huntington's--say that she had no complaints about the services available to them, and that the needs of her family were being met. I have never heard anyone say this in the United States.

ⁱⁱⁱ See Paul E. Brodwin, ed. *Biotechnology and Culture: Bodies, Anxieties, Ethics* (Indiana University Press, 2000); *Empirical Bioethics in Cultural Context: Genetic Confidentiality, Ownership, and Public Participation in the United States and Japan* (Ithaca, N.Y.: Cornell University Dept. Science and Technology Studies, 2003); George Ellison, ed., *Diversity, Difference, and Deviance: Ethics in Human Biology* (Baker and Taylor, 2004); "Feminism Confronts Disability," UCLA, 2002.

^{iv} Stephen Selden, *Inheriting Shame: The Story of Racism and Eugenics in America* (Teachers' College Press, 1999).

^v Nora Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard* (Harvard University Press, 1985).

^{vi} See "Pain and Prejudice in the Santiago Campaign of 1898," *Journal of Inter-American Studies and World Affairs* 18 (Feb. 1976), 59-73; "Sex, Race, and Character in 19th Century Accounts of Cuba," *Caribbean Studies* 18 (October 1978/January 1979), 115-30.

^{vii} *Emma Goldman in America* (Beacon Press, 1984); *Emma Goldman in Exile* (Beacon Press, 1989).