

# **ACTIVIST DISABILITY HISTORY IN THE MUSEUM: How do Visitors Respond?**

## **ETHICS PROTOCOL**

Draft: April 2008

### **STATEMENT OF PURPOSE AND BACKGROUND**

#### Background information and literature; rationale; relevance; contribution

In 2006, organizers of Abilities Festival in Toronto approached faculty in the School of Disability Studies to ask whether we would develop an exhibit of activist disability history. It was an intriguing opportunity, given the state of disability history and the politics of public display. There is a small body of literature on disability history and the disability rights movement (Barnett & Scotch, 2002; Driedger, 1989; Geller & Harris, 1995; Fleischer & Zames, 2001, Hirsch, 1998; Kitchin & Wilton, 2003; Linthicum, 2006; Longmore & Umansky, 2001; Mead & Serlin, 2006, Reaume, 2006, Schwartzberg, 2005; Steinstra & Wight-Felski, 2003). However, these works are exceptions to a more general pattern in which disabled people have been consistently overlooked in historical writings (e.g. Baynton, 2001). Histories that do exist are generally not written from the point of view of people who have lived disability experiences (Yoshida & Panitch, 2007). Further, they almost completely ignore the activist work of disabled people, their organizations and their allies (but see Panitch, 2007; Church, 1995).

This situation is mirrored in the museum. Here again, disabled people are either absent, or present (represented) primarily in and through oppressive relations: as part of the history of “freakery” (Garland Thomson, 1997, 1996) or as objects in the documentation of medical/rehabilitative “progress.” The perspective of disabled people is once again missing. Thus, we could locate only a handful of academic articles at the juncture of disability and museums (Candlin, 2006; Colborne, 2003; Dodd et al, 2004; Sandall, 2003; Steiner, 1991; Weisen, 1991), and nothing at all in the genre of visitor studies (but see Livingstone, Pedretti & Soren, 2002; Roose, 2008, and Weir, 2007 for useful background).

Only recently have disability leaders and organizations begun to make inroads in major cultural institutions. Part of the impetus here is the blossoming of disability arts and culture over the past decade (Abbas et al 2004). Thinking specifically about museums/exhibits, we note the Massachusetts-based Disability History Museum, the Smithsonian’s “History of Polio” exhibit (Serlin interviewing Ott; 2006), and “The Chicago Disability History Exhibit” launched by the National Vietnam Veterans Art Museum. We think also of the Willard Suitcase Exhibit, and the recent publication/website that documents its story ((Penney & Stastney, 2008). Here at home, the Canadian Centre for Disability Studies launched a virtual museum on the disability rights movement, while psychiatric survivor activists in Toronto initiated an archive that

remembers the history of psychiatric in-patients dating from the 1950s. These developments are tremendously promising but none have yet been formally studied – either the disabled producers as they ply their various crafts or the audiences who receive them and their work.

One exception is work done through the Ryerson-RBC Institute for Disability Studies Research and Education (Abbas et al, 2004). Our researchers analyzed written comments from students of Disability Studies who formed an audience for a performance of disability arts and culture called *Art with Attitude*. This preliminary research suggests that to witness a performance in this genre is to be challenged and made uncomfortable as much as it is to be affirmed and uplifted. It is to be "changed" in some way, or pressed to revise or reconcile some aspects of identity and/or place. A contradictory blend of both "light" and "dark" elements, each performance demanded significant processing from audience members -- during and after the event. While fresh openings were possible, the threat to their sense of certainty left many audience members unresolved. One of our conclusions is that "soothing" confirmations of existing views may be all that audiences want from or can understand of disabled artists/performers at this point in time. Our analysis revealed that "changing attitudes" is not an instantaneous and happy enlightenment arising from new and better information. Using art/performance to raise consciousness about a group of people so negatively situated with respect to mainstream culture for so long is troubling and difficult work.

In a moment of such important transitions, it is pressing to document and celebrate a prominent generation of disability leaders that is passing without sufficient record of their labour, achievement and knowledge. Three faculty members from Disability Studies were in a good position to contribute to take up this task. Dr. Panitch was just completing a doctoral dissertation that retrieved the work of "activist mothers" of children with intellectual disabilities from the archives of a major disability organization (Panitch, 2007, 2004); she had good connections to historians internationally. A well-known activist herself, Dr. Frazee had a strong sense of the major players and events in Canadian disability history, as well as a strong role in profiling disability arts and culture (Frazee, **reference rants**). Dr. Church is one of a handful of academics who has documented the work of the psychiatric survivor movement (Church, 1993, 1995, 1997); she had experience drawing community-based exhibit work into museums (Church, 2008; Church, 2003, Church, 2002; Church, 1998; Church & Church, 2003). Together, we have fostered extensive work on disability arts and culture as a "third wave" of disability activism, attending to the work of production by disabled artists/performers and to the work of audiences as viewers of these new art/forms. As well, we had access to activist students and alumni in service organizations across the province, as well as a network of disability activists in community organizations across the country.

In the winter of 2007, we brought these resources to bear on the production of a Special Topics course (DST 506) called *Exhibiting Activist Disability Histories*. Fourteen people participated in this course, which we co-taught through a series of intensive weekends. Mobilizing the notion of "objects that count," we asked each person to arrive with some "thing" that they deemed significant: not so much the "grand" objects of Big History as

the mundane objects of “the history we live” (Lyman, 1981; page). We generated our collective project through group discussions that assisted each participant in identifying the personal stories embedded in the object, as well as its broader social relevance. We supported them in this task by creating two Course Readers that layered together writing on disability history with questions of representation in museums.

Our clear intent was to foster what Ignagni refers to as “art as trouble” (Ignagni & Church, 2008). In other words, in the long and disturbing history of disabled people with art, we sought to destabilize the existing (oppressive) relations of disability. Our collective project was to direct the viewer’s gaze in such a way that they would take up the course of history from the perspective of people with disabilities as the ‘marginalized’ or subjugated Other. With the exhibit as our focus, we wanted to generate an alternative account from the standpoint of disabled people. We hoped it would be a way in which a marginalized group could be heard with unprecedented authenticity and authority (Ignagni & Church, 2008).

Participant exhibitors displayed their work twice that summer: once for fellow students at our annual Summer Institute; and once for people who attended a session at the annual conference of the Canadian Association for Community Living. Simultaneously, the faculty-curators worked with a professional designer to transform what was then a somewhat loose collection of installations into a professional quality display with a cohesive aim, voice and “look.” The final assemblage, titled *Out from Under: Disability, History and Things to Remember*, premiered – as hoped -- at Abilities Festival in October 2007. Appreciated by hundreds of festival-goers, it made history as the first exhibit of its kind in Canada. That exposure, in turn, sparked an invitation from the Royal Ontario Museum. Thus, in April 2008, scarcely two years after our initial deliberations, *Out from Under* will open “under the crystal” at the ROM. What also opens is the opportunity to comprehend more fully the impact of activist disability history on the public consciousness.

#### Research Design; scientific rationale; aims; questions

*Activist Disability History in the Museum* is a study of visitor responses to *Out from Under* beginning at the Royal Ontario Museum but anticipating the exhibit’s movement to other locations and venues in Canada. The idea emerged in conversation between faculty/staff of Disability Studies as we recounted to each other exchanges we had with exhibit visitors. During its initial run, each of us met people – disabled and not – who identified strongly with particular exhibit objects or moments, who found that viewing caused them to remember (or reinterpret) incidents from their past, or who had unexpected insights into their lives and communities. Some people recorded their thoughts in our Comments Book: wonderful, hand-written notes that moved us but left us wanting (to know) more – and from more people. What is it like to engage with a transgressive portrait of disability history? How might transgressive readings of history assist us in re-imagining exhibit-visitor relations? What actually transpires in the process of exhibit-visitor exchange? And how might such encounters inform our larger curiosity about audience responses to disability arts/culture more broadly? On the eve of a major

second opening, we are now in a position to address these questions and others with a formal, systematic inquiry.

This study -- the Museum Study -- is a project of the Ryerson-RBC Institute for Disability Studies Research and Education. In this instance, the Institute's resources are organized through a group of faculty and staff that named itself the *Out from Under Research Group* (OFURG). Formed in January 2008, members are (alphabetical order): Kathryn Church, Catherine Frazee, Esther Ignagni, Phaedra Livingstone, Melanie Panitch, Jenn Paterson, David Reville, and Judith Sandys. With Kathryn Church acting as point person, our purpose is to develop the Museum Study alongside *Out from Under* over the next couple of years. Our tasks will include designing, planning, networking, organizing, reflecting, questioning, discussing, linking, and funding the research process.

OFURG's resources are extended by participation from contributing exhibitors who have signaled an interest in being involved in this research. Members include Carrie Fyfe (student), Sara May Glyn-Williams, Ryan Hutchins (student), Audrey King (disability leader), Sandra Phillips (alumni), Terry Poirier (alumni), Karen Yoshida (university professor), Cindy Mitchell (student), and Ruth Ruth Stackhouse (student). Their primary task will be to aid OFURG in implementing study design. The two groups, acting together, will undertake participant selection and recruitment.

The Museum Study is linked conceptually with a dozen other studies that constitute the Institute's research program. All of them contribute to the emerging field of Critical Disability Studies by focusing on disabling social, political and cultural contexts. Most are designed to reveal the complex invisible "work" -- generously defined -- that disabled people perform in every day/night life including their work as producers of art and culture. Over the past few years, we have deliberately explored (created) connections between disability arts/culture and social science research. *Out from Under* is a prime example. As a cultural product, it provokes questions and suggests problematics for funded research while arts-informed methods contribute practices that enable us to investigate --- and legitimate -- disability culture. Thus, our role as researchers is not just to inquire: it is also to facilitate, catalyze and curate.

*Activist Disability History in the Museum* is a study in the arts-informed study, meaning that it creates opportunities for learning through direct engagement, empathy, and, possibly even, epiphany. With the publication of the first *Handbook of the Arts in Qualitative Research* (Cole and Knowles, 2008), this approach has just achieved a new level of prominence. Each chapter demonstrates how practitioners from a range of disciplines blend the rigor of conventional qualitative research with the sensuality of artistic and narrative forms to demonstrate a new kind of social science. Most use research to create art, expressing their "findings" through the use of fiction, poetry, theatre/drama, visual arts, installation, film and video. Our project will use a major cultural production to produce research.

In their chapter of the *Handbook*, Ignagni and Church (2008) highlight some of the historical "ties and tensions" of arts-informed disability research. Among the possibilities

for enrichment, they mark its capacity to incorporate rather than reject unfamiliar ideas and physical forms, and to illuminate disabling social contexts. Its practitioners are drawn to art forms out of a desire to communicate their research results to audiences who are alienated from the exclusive language of conventional scholarship. Research that draws from art may be able to capture and hold the attention of new audiences, as well as to influence audience interpretations in ways that are more inclusive of difference. It may inspire and compel audiences to adopt new emotional responses, ranging from frustration to solidarity.

However, as Ignagni & Church point out, we must also contemplate the ambivalent relationship that disabled people have with both research and the arts. Each of these endeavours has contributed to a disturbing tradition of normalization and social exclusion. Thus, “For disabled people, it is hardly relevant whether the inquiring gaze is motivated by aesthetics or a desire for knowledge. Either way, it is one more instance in which the doubled practice of ‘the look’ occurs. Disabled people are looked at as sites of inspiration, curiosity and exploration. And this only invites the exclusionary practice of ‘looking away’ (Ignagni & Church, 2008).

Our interest is in both sides of this dilemma. By foregrounding *Out from Under* in a major Canadian museum, we appeal to new audiences – the general museum-going public -- at the same time as we face new interpretive risks. As researchers, it is important for us to find out whether and how public exhibit and disability can come together in meaningful ways. What sense do audiences make of activist disability history, and of its presentation in this way? Is exhibiting possible without continuing old oppressive traditions? Or have we simply reproduced the dynamic of “the look” and the “looking away” – as ongoing practices of exclusion rather than inclusion. Can we produce representations of disability that challenge their ‘official’ counterparts in medicine, technology, neo-liberal economics and religion? Will visitors refuse to be dislodged from dominant interpretive frames? If not, what are the implications of our failure? (Ignagni & Church, 2008)

### Justification for involving humans

The project is a study of human history and cultural life. It cannot be done without direct human contact.

## **SUBJECTS**

### Subject Characteristics

(number of subjects including gender, age range etc.)

We anticipate speaking to roughly 270 people using a combination of intercept interviews, small focus groups and other group discussions. All participants will be visitors to the Royal Ontario Museum who have viewed “Out from Under.” Some will be casual visitors who encounter the exhibit as part of their larger tour of the museum.

Others will be “deliberate” visitors invited by the research team and its exhibitor/ collaborators to attend and comment on the exhibit. Within this “pool,” we are not seeking demographic representation to produce a sample in the usual statistical sense of a priori categories such as gender, age range, etc. Instead, participants will become part of the study either through self-selection or through their connection with a member of the research team or our exhibitor collaborators.

### Criteria for Inclusion

Visitors will include themselves in the intercept interviews by verbally agreeing to speak to the interviewer when they are approached at the exhibit. Visitors will self-select into group discussion by showing up at the right room and time in response to invitational posters strategically located throughout the museum on the day of the event. Focus group participants will be purposively selected by members of the eight-member research team and our nine exhibitor collaborators. Reflecting on our personal and professional networks, each of us has identified one or two groups whose views on the exhibit are significant to the discussion we are stimulating through this research. Some of these people are located in environments that are constituted by disability experience/ debate; others are located within influential professions or sectors. In both instances, whether through resonance and/or dissonance with the exhibit, we are selecting people who can enrich the dialogue around disability history.

### Special Populations

This study is rooted in Critical Disability Studies, a field in which the terms “population” and “special population” signify a long history of programs and social arrangements that have often resulted in the segregation and isolation of disabled people. Indeed, this recognition is a strong theme in the exhibit that we are inviting participants to view and discuss. Our focus groups will include people with mobility restrictions, body/sensory differences and psychiatric histories. Some will be adults designated as “cognitively impaired,” some will be disabled youth (under 18). It is difficult to imagine study participants with more of an investment in and a right to study participation. In a unique turn, not including members of “special groups” here would mean excluding them from their own history.

### Recruitment Source

The ROM is our source for participants in the intercept interviews and group discussions. The research team and our exhibitor/collaborators are the source of focus group participants. Drawing on our networks, we have assembled a list of people with varied affiliations who are keen to view and discuss the exhibit. They include labour union members, community college and university faculty, university students and alumni, retirees, human rights lawyers, journalists, and government bureaucrats. Some participants are connected with or located in groups, organizations or networks whose members have direct and/or family experience of restricted mobility, cognitive impairment/difference, and/or psychiatric histories. Others are community service

providers who have jobs in various parts of the service sector that shapes the lives of disabled people. However, organizations are not a recruitment source in our process; participants will not represent agencies or organizations. This study makes no use of any formal database such as institutional, hospital or service agency records.

### Recruitment Methods

For the intercept interviews, interviewers located within the exhibit will directly approach adult visitors who have spent fifteen minutes or more in the exhibit, and who are not responsible at the time for another visitor or child. For group discussions, we will use posters, placed in strategic locations throughout the ROM, to invite visitor participation at particular times, on particular days. Focus group participants will be invited by the member of the research team or exhibitor/collaborator who identified them as significant, and took on the task of organizing their attendance. The invitation and arrangements will occur through face-to-face contact supplemented by email and telephone contact.

### Informed consent process

For intercept interviews, a bilingual sign, indicating in large type that a visitor study is in progress will be posted in the exhibit hall at all times when intercept interviews are in progress. Potential participants will have been observed to spend at least 15 minutes viewing the exhibit before an interviewer approaches them. Researchers will identify themselves using a script that we have developed. The interview will proceed only if the visitor agrees. If the visitor is willing to be interviewed, the interviewer will ask to digitally record the interview, as well as the agreement to participate. We will use Participant Agreement forms with any visitors who agree to be interviewed but decline to be digitally recorded. We will make Agreement forms available to any visitors who want one to take one away. The interview will take no more than ten to fifteen minutes, and can be terminated by the visitor at any time.

Group discussions will be moderated by a member of the curatorial team from the exhibit paired with another member of the research team or exhibitor/collaborator. Moderators will introduce the sessions by indicating that we are hosting them for research purposes and that a research assistant is taking detailed notes. Participation Agreements will be circulated at the start of the discussion and collected immediately. We will make Agreement forms available to any visitors who want to take one away. Moderators will look to questions from participants to shape the discussion but our focus group questions will serve as a guide here as well. Discussions will run for roughly 60 minutes, or as long as discussion is lively. Visitors can come and go at their own discretion.

Everyone approached or asked to participate in a focus group will be legally competent to assent and/or give informed consent either directly or through a legal guardian. Any youth under 16 (sixteen) will be given assent forms and their guardians will fill in consent forms. Wherever possible the relevant forms will be circulated ahead of time, either electronically or by hand, for participants to read and consider. Each discussion will open with an opportunity for people to ask questions about the Agreement before

they are collected. Agreement forms will be available to any participants who want to take one away. Focus group participants can terminate their involvement in the group at any point in the discussion.

### Study location

All data collection will take place at the Royal Ontario Museum between April 17, 2008 and July 13, 2008. Intercept interviews will take place in or very close to the exhibit itself. Group discussions and focus groups will take place in rooms available at the ROM for this purpose.

### Potential problems

Telling disability history is about telling difficult stories (Sendell et al, 2005). “Out from Under” may cause some visitors to feel discomfort with respect to the realities of life for disabled people in the past, negative societal responses and ongoing prejudices. These are challenging themes for public presentation, particularly if – as with the casual ROM visitor – you are not expecting to encounter them on your museum journey. Visitors who are uncomfortable or disinterested are not likely to stay in the exhibit long enough to be approached by one of our interviewers. Nor are they likely to respond to a poster that invites group discussion. By contrast, focus group discussions may draw in people who are unfamiliar with elite institutions and exhibit forms. The ROM’s “grandness” and privilege may be discomfoting or alienating to those who are poor and in other ways disadvantaged. We are relying on the judgment of the research team and our exhibitor/collaborators to select participants who are intrigued rather than daunted by our entry point in the museum – and who are curious and excited about the prospect of viewing the exhibit. In addition to paying the entry fee for participants, we will lay careful groundwork with them through preparatory conversations undertaken by the person who organizes their participation. While participants may volunteer personal information in the course of discussion, we are seeking their responses to the exhibit rather than soliciting their personal stories. We will be available for follow-up conversations to discuss any issues that arise for participants.

### Risk Management

The procedures will include:

- Selection through networking that relies on researcher knowledge and judgment;
- Voluntary participation which may be terminated at any time;
- Careful preparatory conversations
- Transparency of methods;
- Participation Agreement circulated ahead of time;
- No personal documents sought;
- Follow-up discussions if/when necessary

## **RESEARCH DESIGN AND METHODS**

### Research Design/Methods; procedures; tasks

This project is an arts-informed study in the interpretive (qualitative) paradigm. Beginning from a professional display of selected objects and narratives, we will collect data using three methods: intercept interviews with people who visit the exhibit as part of their ROM experience; focus groups with participants who are purposively selected; and group discussions with interested ROM visitors. This mix of approaches will enable us to engage a range of participants in different forums over varied lengths of time.

The intercept interviews will be structured by a brief set of open-ended questions, and conducted over a specified period of time by 4-5 Disability Studies graduates under the supervision of exhibitor and co-investigator, Dr. Phaedra Livingstone. Group discussions will be led by one member of the curatorial team paired where possible with an exhibitor. A research assistant will keep detailed notes of the discussions, with particular attention to the questions asked. The planned discussions, 2-3 in number, will be open to any member of the ROM's visiting public, and will allow us more time with "regular" visitors than the intercept interviews. We cannot estimate the numbers of participants for the intercept interviews or the group discussion; these aspects of the methodology are positively open to circumstance.

Focus groups of 6-8 people will be conducted using an interview guide that encourages remembering, reflection and story-telling. Each member of the research team has selected two groups that they want to tour through the exhibit, and talk with afterwards (8 people x 2 groups = 16 x 8 = 128). Similarly, exhibitor/collaborators have selected a group that they would like to draw in (9 people x 1 group = 9 x 8 = 72). In total, the focus groups we have planned will take in a maximum of 200 people, selected for locations, relations and expertise that we deem important. Some groups will be facilitated by the person who organized them and knows them best; others will be led by a different member of the research team. The choice here depends on the judgment of the researcher/collaborator. Most groups will include two facilitators: one to lead the discussion and one to observe and manage recording and paperwork. All focus group discussions will be audio-taped, and transcribed.

Data analysis will be done first individually and then collectively. Each group facilitator will be responsible for repeat readings of his/her transcript, surfacing key comments and stories. The entire group will meet several times to "pool" the interpretations we have begun to formulate, to develop a collective sense of participant dynamics and conversations. Together, we will forge common analytic directions that will form the framework for future iterations of our research process, and for documentation of our results.

### Tests, questionnaires and interview guide

We have developed two interview guides: one for the intercept interviews and one for the focus groups. While the first is much shorter than the second, there is some overlap in the questions. This is not a comparative study but we look for a measure of consistency in discussion across our three methods.

### Benefits

The primary benefit of the study is to build knowledge of public responses to a cultural form that has been created by the activist disability community and its allies. Public understanding of disability is “stuck” in pre-scripted perceptions that swing between tragedy/pity/shame, and courage/individual achievement/inspiration. It is important for us to understand whether the mundane objects and alternative narratives that we have foregrounded through the exhibit can challenge these powerful tropes and the professions/industries that benefit from them. As such, the study will increase our understanding of the work that disability arts and culture can do to support the disability rights movement and its activism. In terms of academic scholarship, the contribution to both Disability Studies and Museum Studies will be significant. This study pioneers museum visitor research in relation to disability history, ongoing issues and debates. We know of no other studies conceptualized in this way, fostering these collaborations, using this combination of methods employed, across these groups. This initial implementation acts as a “pilot” for further iterations of the study in other locations where the exhibit may be installed. It marks the next phase of development for a larger program of cutting edge disability research organized through the Ryerson-RBC Institute for Disability Studies Research and Education.

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