

Creating, archiving and exhibiting disability history: The oral histories of disability activists of the Carleton University Disability Research Group

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Abstract

Building a disability archives that is accessible is an ongoing challenge. At Carleton University in Ottawa, Canada, this work began a decade ago with the formation of a modest collection of scholars interested in disability issues. The Carleton University Disability Research Group developed as a collective of scholars, graduate students, and non-governmental organisation workers from the fields of social work, engineering, history, library, and archives, including people with disabilities. Since 2013, it has worked to collect, archive, discuss and display histories of disability in Canada, using various media. This paper documents and analyzes the aspects of this work linked to information studies, from the role of archivists and librarians to the making of archives and exhibits with, for, and about people with disability. It presents innovative decisions, introduces unexpected benefits for all in the light of the project of a critical disability archival method and discusses the potential of universities as a site of practice. It takes its most recent project, the *Oral histories of activists in the disability rights movement in Canada (1970–2020)* as the main case.

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Introduction

This paper addresses the importance of both bringing topics related to disability into the archives and making

archival repositories accessible to people with disabilities. We begin with a brief review of how the Disability Research Group of Carleton University (CUDRG), located in Ottawa, Canada, has assembled archival materials related to disability, for over a decade of research, exhibitions, workshops and teaching about disability rights issues. We address these issues mainly through a discussion of our project, *Oral histories of activists in the disability rights movement in Canada (1970–2020)*, which is the latest stage of a larger, multiforme and enduring work involving communities of people with disabilities, university students, and scholars. We then turn to experiments in making archival records available to people with disabilities, digitally, and in person, in collaboration with Carleton University’s Archives and Special Collections (ASC).

As we reflect on the collection and display of objects, papers and testimonies which accompanied our activities, we argue that the inclusive and open ethics of work that has governed our meetings and experimentations from the start might have, somewhat inadvertently, helped the CUDRG produce the very kind of documents, and invitations to engage with them, sought by proponents of a critical disability archival method (Brilmyer, 2020; White, 2012). Three strategies adopted from the start, for all activities of the group (the constitution and opening of archives was never the only goal of the collective) coloured our attitudes towards historical documentation. These were: considering the archives and the archivists as one crucial component of the team; focussing on technologies (material and immaterial) produced, used, and fine-tuned by people with disabilities; and finding, as much as possible, the voices of people with disabilities to tell the stories. We conclude with a discussion of the possibilities offered by university archivists and public historians to host multiforme endeavours capable of fostering a critical disability archival method, and a more equitable access to the documents of disability history. While this paper is largely descriptive of our processes, we regarded it as an important foundation for potentially developing and expanding critical disability theory.



1. Bringing the topic of disability into the archives: Origins and approaches of the CUDRG projects

Disability issues are under-documented in archives. There are several ways to address this gap: new archival records can be created; existing records can be located and archived; and disability-related aspects of existing collections can be highlighted and made accessible (Richards and Burch, 2018). Questions of disability and sickness can be understood within wider questions of “bodily and mental norms” which confront disabled communities (Brilmyer, 2022, 2020). Our group has experimented in all these directions.

Established at Carleton University in 2013, the Carleton University Disability Research Group (CUDRG) is a team of professors and graduate students from many disciplines, such as social work, engineering, history, library sciences and archives, as well as NGO workers and independent scholars, all including people with disabilities. From its creation by medical engineer Adrian Chan and social worker/historian Roy Hanes, its membership and decisions have been driven by a common concern to showcase the wealth and ingenuity of disabled people’s past knowledge and practices to classrooms of students bound for work with disabled communities. They evolved with the rhythm of hirings, research assistantships, graduations and retirements. On the way, they attracted those on campus and in the nearby region of the national capital who wanted these stories told, for a variety of personal and professional reasons, from an interest in the history of social policies, to lived experience with a sensory, physical or mind impairment, long-lasting or temporary, to work in making libraries accessible, or local involvement in human rights activism. “Nothing about us without us,” a principal familiar to practitioners of critical disability studies, expresses the commitment of placing disabled peoples at the centre of the research, and this principle was applied to the composition of successive research teams. It kept the choice of topics wide open and made for a continuous discussion of methods, from one project to the next, all key aspects for research accountability (Hansen, *et al.*, 2018; Marshall, 2013; Act to Employ, 2022; Richards and Burch, 2018). As a result, the CUDRG has looked for, received, studied and displayed histories of disabilities and technologies in Canada, on topics determined collectively and incrementally, using several types of archives.

In the Fall of 2022, *Oral histories of activists in the disability rights movement in Canada (1970–2020)* became our fifth online exhibit. Previously, the CUDRG has experimented with several media of

dissemination: workshops, presentations in classrooms, school fairs and scholarly conferences, community site visits, were all tried and adjusted. To this day, virtual exhibits have remained the most rewarding media. The first two virtual exhibits, *Mobility histories: The wheelchair in Canada: Accessibility, technology and society* (Smith, 2015) as well as *Envisioning technologies* (Robertson, 2016), focussed on actions and ideas of people with disabilities in the design and development of mechanical devices. The collective strategies, representations and initiatives required to make, use and distribute these technologies directed our attention to the themes of two subsequent exhibits, *Canada and the founding of Disabled Peoples' international*, and *Interdisciplinary anticipations of a non-normative tomorrow* respectively (Patterson, 2019 and 2022b; 2021). A sixth project is underway, about *Accessibility, inclusion, and disability: Connecting scholars with practitioners*, which will be exhibited in late 2023.

Perhaps more vividly than any other documents, recordings of activists' voices have invigorated the histories that the CUDRG wanted to tell. To develop the three first exhibits — on histories of wheelchairs, histories of technologies for people with visual impairments, and on the movement “Disabled Peoples' International” — CUDRG researchers used interviews archived in various depositories; they also conducted interviews themselves (Smith, 2018, 2017; Robertson, 2018a, 2018b; Patterson, 2018). Three examples are discussed.

In 1995, Mary Tremblay, historian of medical rehabilitation and disability policy, interviewed Joanne McLeod, one of the founders of the New Brunswick chapter of the Canadian Paraplegic Association (CPA); McLeod was interviewed again in 2018 by CUDRG researcher Dorothy Jane Smith. Her stories are about her years of struggle with issues of accessibility and the role of the wheelchair in her life (Tremblay, 1995; Smith, 2018, 2017). A few months later, as CUDRG researcher and co-author of this article, Beth Robertson consulted the collection and archives of Ingenium: Canada's Museums of Science and Innovation for the exhibit on technologies designed for and by innovators who were blind or low vision, she found the forgotten audio cassette of an interview with Roland Garlneau. Garlneau was a Canadian self-trained machinist and engineer with two percent vision, who in the 1960s had developed a machine that automatically transcribed written text into Braille. Adrien Filiatreault conducted an interview with Garlneau in 1987 (Robertson, 2018b), which was then collected and stored within Ingenium's collection. Robertson arranged to have the recording digitized, transcribed, and translated into English (Robertson, 2018b). Finally, when Ryan Patterson prepared the CUDRG exhibit on Canada's role in the founding of the Disabled Peoples' International, he relied indirectly on 22 interviews Diane Driedger had conducted in the 1980s to write a thesis in history on the “The origins and history of Disabled Peoples' International”; three decades later, Patterson had the privilege of talking to Ms. Driedger about her own interviews (Patterson, 2018).

Beside these three exhibitions, one collaborative work of another kind brought interviews to the CUDRG collection. In 2018, Carleton's Archives and Special Collections became the repository for the recording of the activities behind the scenes of the Royal Assent of Bill C-18, the *Accessible Canada Act* (<https://www.canada.ca/en/employment-social-development/programs/accessible-people-disabilities/act-summary.html>). The legislation was aimed at making Canada a barrier-free country by removing impediments to accessibility in services under federal jurisdiction. At the invitation of one promoter of the bill, Max Brault, who had partnered in several Carleton initiatives, CUDRG member Beth Robertson entered in the team that planned, conducted and recorded the event, alongside digital media producer Dean Emerick. Robertson and the CUDRG archived the raw footage, which was showcased in a small documentary film (Brault, 2019).

Thus, it was for ethical and esthetic reasons that the CUDRG collected first-hand accounts of disability activists and makers, an endeavour which special education scholar Elizabeth Bredberg categorizes as “experiential” disability history (Richards and Burch, 2018). By 2019, another reason had emerged; the recording of the testimonies of disabled peoples in communities served by the CUDRG was gaining urgency. Many disability activists were now entering their senior years and gathering and preserving their stories was crucial for future writers, teachers, and developers of exhibits. In 2020, the group began working on the project *Oral histories of activists in the disability rights movement in Canada (1970–2020)* (referred to in this paper as *Oral histories*).

An important catalyst for this new priority was the graduate work of Hollis Peirce, an original member of the Carleton University Disability Research Group. Peirce centered his M.A. research on accessibility issues in

institutions of higher learning. For his thesis, “Academic accessibility: A case study of Carleton University, 1942–2019,” he interviewed Carleton University veterans devoted to making the institution accessible (Peirce, 2019). As a history student with a disability, Peirce offered knowledge, experience of personal journeys, and skills in oral history. Those present at the oral defence of his graduate work shared the sense of importance he placed on identifying and preserving the historical records of forgotten actions. Members of the jury were taken by the immediate need to continue with the work where the thesis finished, not only about access at Carleton University, but beyond. Peirce would later join the research team of *Oral histories* as an independent scholar and consultant.

Roy Hanes, Professor at Carleton University with expertise in work with disabled communities and disability history, and founding member of the CUDRG, was present at Peirce’s thesis defence. He had developed the first course using a critical disability perspective in a Canadian school of social work and contributed to the development of the disability studies program at Carleton. Having worked with disability rights activists for three decades, Hanes was well-placed to see how little of their work was documented (Hanes, 2017). Sadly, shortly after the gathering over Peirce’s thesis defence, one of the people Hanes had wished to interview passed away. Mary O’Brien, a medical doctor who began a general practice at the Health Services at Carleton University in 1969, had played a pivotal role in the development of the Disabled Students Program at Carleton (Dr. Mary Stuart O’Brien, 1925–2020, 2020). As Hanes witnessed the deaths of many aging activists, he grew increasingly concerned that legacies would be lost if older activists were not interviewed immediately.

To be clear, similar projects were developing elsewhere; the main one was the 2021 Manitoba League of Persons with Disabilities (MLPD) Project led by Carlos Sosa, in collaboration with the Oral History Centre (OHC) of the University of Winnipeg. Sosa conducted nine interviews, which he deposited at the OHC and showcased on the Web site of the MLPD (Sosa, 2019, 2014). He generously shared his experiences and expertise with the CUDRG, providing advice and encouragement, and giving our group access to documents. We were able to compare our list of interviewees with his and agreed to link our respective databases in the future.

2. Creating disability archives: methods and challenges of the *Oral Histories* project and earlier archival creations of the CUDRG

The *Oral histories* project began in March 2020 when two CUDRG colleagues and co-authors of this paper, social work educator Therese Jennissen and historian Dominique Marshall, developed a research plan to interview disability rights activists in Canada, to follow up on the wish of Roy Hanes mentioned earlier, who was about to retire. The interviews would be presented in a new digital exhibit, hosted on the Web site of the CUDRG (<https://cudisabilityresearchgroup.wordpress.com>). As the collective adapted older ways of working to the new *Oral histories* project, additional members entered the team, questions cropped up, important lessons were learned, and questions persisted.

The two principal investigators of *Oral histories* worked with Chris Trainor, Head of the Archives and Special Collections of Carleton University and co-author of this article, to facilitate the process of depositing these audio-visual documents in the archives (Archives and Special Collections, Carleton University). CUDRG member and specialist in the history of deaf education Sandy Barron, joined the group to interview in this field (Barron, 2021). Three social work Ph.D. students became research assistants (RAs) and an undergraduate student in history joined as the administrative assistant. As mentioned earlier, Hollis Peirce came back to campus to help identify potential interviewees and construct an appropriate questionnaire, as well as to attend most interviews. All team members had professional or voluntary experience working or living with people with disabilities, and Peirce is a disabled person (Carleton University Disability Research Group, 2020a).

The first job of the *Oral histories* team was to complement and investigate a list of people to interview, beginning with a bank of names of individuals Roy Hanes identified as having played a central role in the disability rights movement, most of whom were people with disabilities ([Figure 1](#)). We knew early on that we

were barely scratching the surface of the work that could be done for this project. As the list of interviewees grew, we made decisions about what was feasible given a fairly tight budget and a time frame of one year. The *Oral histories* project focused on people who were activists in the disability rights movement in Canada between 1970 and 2020.



Figure 1: Overview of the project *Oral histories of activists in the disability rights movement in Canada (1970–2020)* — Design: Margaret Janse van Rensburg.

In the selection of interviewees, we struggled with the issue of fairness in portraying the group whose stories we wanted to tell, wary, for instance, of an initial overrepresentation from Manitoba and Ontario, and from academics. We recognized the importance of representation based on Indigeneity, French heritage, gender, race, and region. We also worked with wide definitions of the terms “activist” and “activism”, aware, as Peirce’s earlier work had pointed out, that people we defined as such might not see themselves this way (Peirce, 2019; Nepveux, 2015; Williams, 2015). We tried to work through these types of issues while at the same time adhering to an urgent timeline.

We aimed to develop and nurture trusting relationships with “knowledge keepers,” a practice cultivated by earlier CUDRG projects. The value of an open questionnaire with pre-established questions that would only serve as a checklist for the conversation, was understood by all; it provides interviewees with opportunities to direct the conversation. The trust developed by members of the team, and by Carleton’s reputation of being friendly to people with disabilities (Rubinstein, 2021; Eldib, 2021) went a long way to building open and transparent relationships with the people we interviewed. In the tradition of storytelling, we considered the conversations to be a partnership, around a shared sense of the value of bringing these experiences to light (High, 2018). Coming from various social science traditions, disability studies, and the community of activists, some colleagues questioned the fairness of the CUDRG practice of not providing the interviewees with an honorarium, beyond paying for the costs of participation, given the longstanding lack of power of

people with disabilities. This debate amongst Canadian researchers was regularly discussed at team meetings (Cheff, 2018).

Pandemic restrictions added technical and personal challenges to the process of conducting interviews, and all meetings took place remotely. The CUDRG continued to be mindful of the abilities of the interviewees. Earlier on, for instance, during an ongoing project about housing for individuals who are deafblind, CUDRG researcher Sandy Barron filmed an interview with a deafblind person with the help of an intervenor. He found that:

[c]onducting an interview through an intervenor is challenging. Tactile sign language (a modification of the British Sign Language two-hand system felt by the Deafblind signer and returned through finger spelling) is very difficult to shoot, so ensuring that the signer is being well served by the intervenor can be difficult. It is important to have the signer work with an intervenor of their choice or that they trust. It is also key to have the Deafblind interview subject approve the resulting transcript (Barron, 2022).

In the same spirit, the research team of the *Oral histories* project sought training from experts at Carleton University's Paul Menton Centre for Students with Disabilities to transform the projects ethics consent forms into accessible online fillable PDF documents. With these parameters in place, we were able to collect the oral histories listed in [Figure 1](#).

The 2018 work on the *Accessible Canada Act* indirectly led to adding an interview to the *Oral histories*. Max Brault, the producer of the documentary, experienced first-hand the difficulties wheelchair users encountered in using the elevator of the Carleton University building where most meetings of the CUDRG took place, Paterson Hall. Brault introduced our research group to the software engineer, Ke Wang, who had designed a touchless app accessible through smart phone technology to operate elevators to help wheelchair users like himself. Engineers of the CUDRG convinced the managers of the university buildings to support Ke Wang's work to retrofit the elevator of Paterson Hall, by allowing him to prototype a version of his app compatible with the standards of public buildings and supporting the project financially. Enriched by Peirce's extensive notion of "activism", we considered Ke Wang, whose device would later be adopted for use in the Toronto airport (Matthieu, 2020; Szperling, 2020), to be a good candidate for the project in his own right, and he accepted to be interviewed for the *Oral histories* project. This illustrates well how archival collections conducted by the CUDRG are part of a chain of trust; equipped with a variety of tools, the group has been able to develop approaches to issues of disability across communities that leverage several perspectives and use the methods of several disciplines. This cross-fertilization continues to have a synergizing effect on the group's archival practices.

Some interviews projected by *Oral histories* gave rise to unanticipated opportunities of another nature. The example of the group of family and friends of the late Joanne Francis, a Mohawk woman of the Wolf Clan from Akwesasne, a community near Cornwall, Ontario, is the most telling (Obituary for Joanne M. Francis, 2016). CUDRG Research Assistant, Ann Seymour, connected with Francis' family to see if they might agree to tell her story. They ended up discussing the creation of a new archival fonds and an exhibit, possibly located in their community, to host the vast number of materials Francis had kept during her years of activism. Seymour presented many possible ways by which the CUDRG could accompany this larger endeavour. We provide below a brief sketch of future efforts to honour Joanne Francis and her work with disabilities, based on Seymour's facilitation, and with the consent of members of the Francis family.

Joanne started her career as a nurse. When a car accident left her a paraplegic at the age of 21, she quickly discovered the many challenges that persons with disabilities experience. She then shifted her career focus to social work, receiving a Master's of Social Work degree.

She worked for the Mohawk Council of Akwesasne as a client advocate and social worker. Joanne dedicated her life to eliminating challenges that prevent self-sufficiency and a quality of life for the disabled community and their families.

Joanne fearlessly fought for the rights of people with disabilities until her untimely passing to the spirit world at age 59. Joanne leaves a legacy of work that has resulted in impactful changes in her community, Canada, United States and the World. She has made a lasting impression on those who were fortunate to witness her energy, drive and passion for life.

Her family is enthusiastic about keeping her memories alive and preserving the history of her extensive work. We have an opportunity to interview Joanne's family who will be able to provide a valuable context for her records.

Joanne's records will add an important dimension to the oral history project and open up opportunities for understanding more about the complexities of the intersection of Indigeneity and disability, as well as intersectionality more generally (Seymour, 2022).

The conversation with the family of Joanne Francis represents one of several occasions when CUDRG researchers have supported the archival deposit and public display of disability-related documents. On other occasions, the survival of disability-related archives was much more uncertain than for the Francis family, who were aware of the importance of the public life of their sister and cousin. At other times which research protocols will keep confidential, the actions of the group have encountered difficult debates, not infrequent within communities of activists, over which member has the authority to deposit archival documents and where to deposit them.

3. Bringing new disability documents to the archives, and uncovering old ones

Whether we stumbled over them or actively looked for them, we guaranteed the preservation of several disability-related documents and artifacts, providing this somewhat eclectic ensemble with a renewed value. During her research on the inventions of James Swail, an engineer at the National Research Council of Canada who was blind, CUDRG scholar Beth Robertson collected several machines that were developed by, and for, people who were blind: a reading machine; a "talking typewriter", and a computer punch-card reader containing an early speech synthesis software called Spellex (Figure 2). Invented in the 1960s by Dr. Michael Beddoes and Dr. Ching Suen at the University of British Columbia, and prototyped with the assistance of James Swail, the Spellex system was "developed to aid the blind in the use of computer and office equipment without sighted help". Ching Suen became Director of the Centre for Pattern Recognition and Machine Intelligence (CENPARMI), at Concordia University in Montreal, where Robertson visited him, and received his kind donation. The Spellex system is considered a crucial part of the history of machine intelligence, pattern learning and speech recognition (Suen, Beddoes and Swail, 1976; Robertson, 2018a). These objects are now located in the vaults of Carleton's ASC, awaiting archival processing.

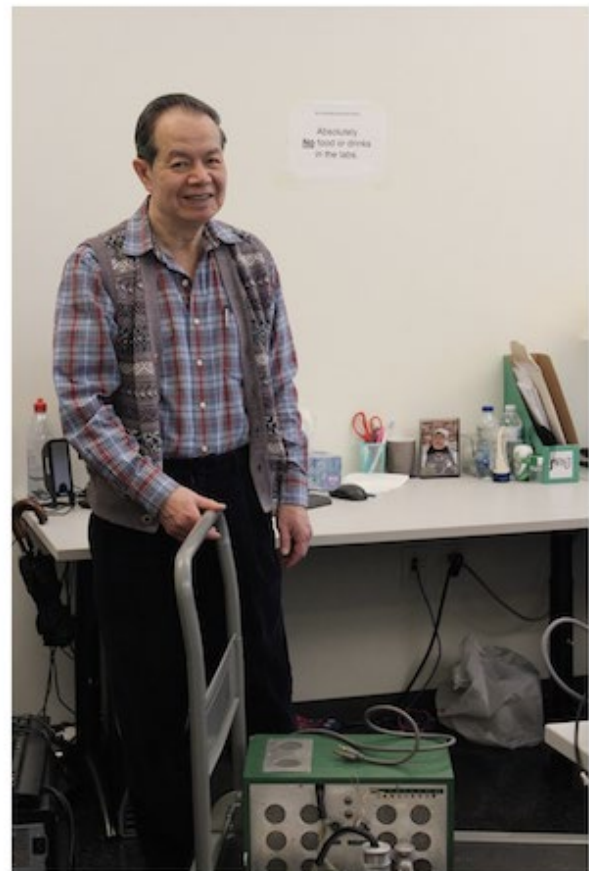


Figure 2: Right: Dr. Ching Suen with with plaid shirt and sweater vest, standing on one of the labs of CENPARMI, with scanner/reading device on pushcart below him.

Left: “Talking typewriter” developed by Dr. Michael Beddoes and Dr. Ching Suen in the late 1960s at UBC on table in the labs of the CENPARMI.

Donated to ASC by Dr. Suen in 2018. Not catalogued yet (Carleton University Disability Research Group (CUDRG), 2019). Photos: Beth A. Robertson.

Another set of records on its way to ASC is the collection of interviews of social work pioneers conducted by Karen Hill in 1983–1984, with support from the Canadian Association of Social Workers, for whom she used to work. Hill produced 53 video-based oral histories, which were also transcribed, and at least eight of them address questions of disability. Hill’s intention was to collect and preserve the stories of these pioneers for future use by social workers, but not much happened to the copies she deposited at Library and Archives Canada, where they can be consulted at a cost. Recently, another set of video cassettes preserved by co-author Therese Jennissen was lent to McMaster University professor and scholar Tara La Rose, who digitized all of them for her project on the history of social work (La Rose, 2020), and will deposit them at ASC. It is hoped that once visible on Canada’s collective catalogue of digitised documents, the complete set of interviews will provide a new insight on the thoughts and actions of disability-related social workers.

The collection of these varied artifacts and documents (talking typewriter, a punch-card reader and oral histories of social workers) into a shared space occurs only when a connection or common link can be made between/among them. The challenge of identifying the common thread of disability history in eclectic artifacts requires both knowledge and skill. While we may accidentally stumble upon an artifact, the researcher or archivist must be able to see its intrinsic value in order to pull it into the collection. This typically happens only when a “disability perspective” is adopted. When this occurs, and archival materials that in other contexts may seem unrelated becomes “related,” it can create an opportunity to develop an enriched understanding of

disability and the potential to create new knowledge (Brilmyer, 2020).

Another important aspect of developing disability archives is making disability visible by highlighting the existence of little-known documents that are already deposited. An important challenge in establishing disability archives is that disability-related memorabilia are part of collections that are not recognized or understood to be related to disabilities. Hansen points out that while museums and archives may contain disability-related artifacts, linking them to disability happens only after they are examined from a disability studies perspective (Hansen, 2018; Brilmyer, 2022). For instance, in 2018, a fellow librarian attending the launch of the “Envisioning technology” virtual exhibit remembered the Braille map of the tunnels of the University, now famous for the access they provide to wheelchair users, produced by an undergraduate student three decades earlier ([Figure 3](#)).



Figure 3: “A tactual map of the tunnel system at Carleton University” produced in 1983 as part of course work in geography by Lorraine J. Moss (Moss, 1983). Photo: ASC.

Elsewhere, papers collected for their value to the history of humanitarian aid can be read against the grain to make sense of the past of people with disabilities, as in the case of leaflets located in the recently acquired collection of documents from the Canadian Red Cross pertaining to people disabled by landmines in protracted conflicts (Archives and Special Collections, ICRC fonds; MacKay, *et al.*, 2019) (Figure 4). The fonds of the Match International Women’s Fund includes letters about the shipment of wheelchairs from Chilean Canadian exiles to their homeland which have not been studied yet; they were brought to light during an event commemorating students and professors transnational solidarities in the aftermath of the military coup of 1973, at which ASC was invited (Murray, 2018; Archives and Special Collection, Match International Women’s Fund fonds). Information about disability in countries of the Global South, not unlike the history of Mohawk activist Francis mentioned above, help to offset “histories and archives [of disabled people that] continue to have a strongly Euro-American orientation” [1].

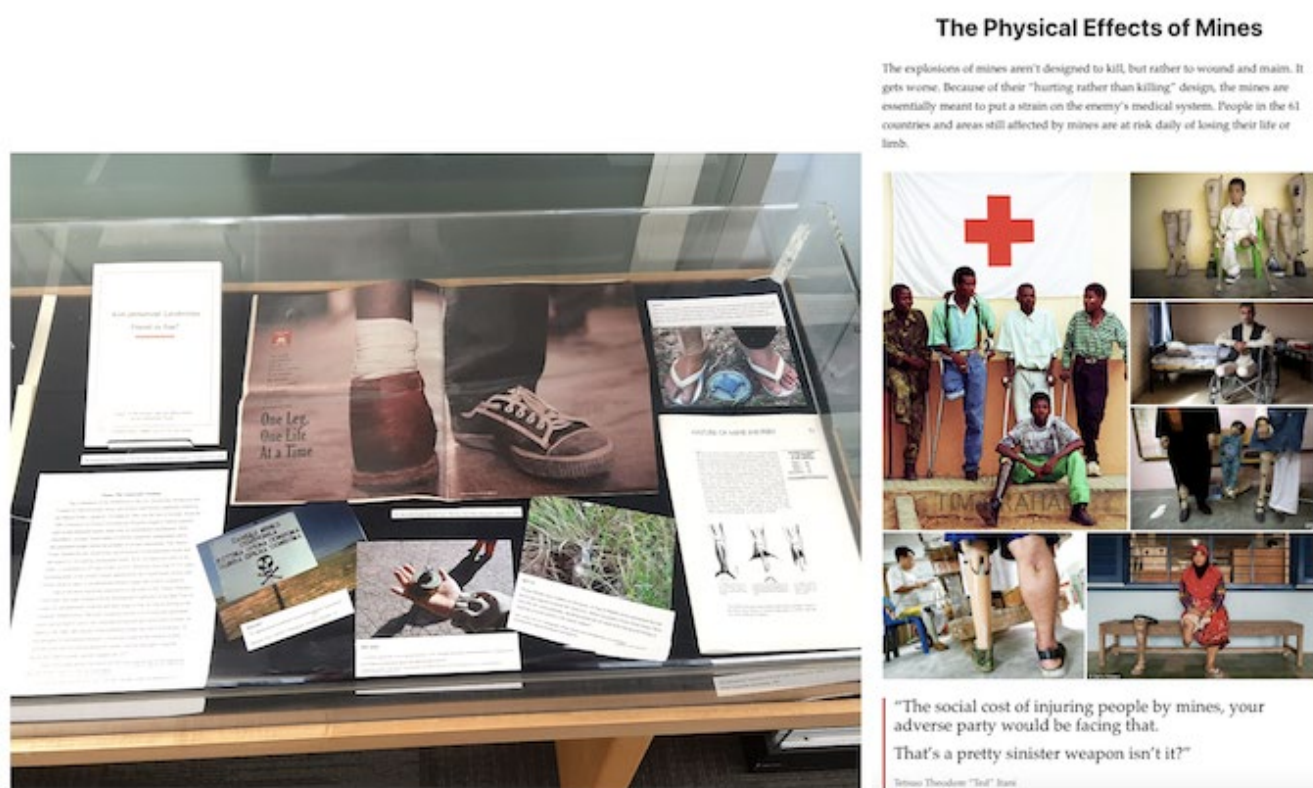


Figure 4: Exhibits of items of Carleton University Archives and Special Collections, ICRC Fonds, on land mine injuries rehabilitation and prosthetics, prepared in 2019 by undergraduate students of a course on the history of humanitarian aid. Left: physical display in the display cabinets of the archives; Right: virtual exhibit in a blog posted by the CUDRG (MacKay, *et al.*, 2019). Photo: Dominique Marshall.

4. Designing exhibits for access, and accessing exhibits

Having addressed the importance of bringing topics related to disability into the archives, we turn our attention to the question of opening archival repositories to people with disabilities. It is no secret to scholars working in the tradition of critical disability theory, that the very failure to provide access to archival resources to disabled people is intimately linked to the ways by which society has failed to adequately document the history of disability activism (Hansen, 2018; Millar, 2017; Snider, 2014a).

Creating physical exhibits of disability-related historical documents represents one way out of this conundrum. To show documents about disability and technology in Canada past in the most accessible way, CURDG member Beth Robertson consulted with disabled communities, experts, and worked with CUDRG research assistants. Two touring exhibits of *Envisioning Technologies* provided an opportunity to pilot a variety of means: QR codes linked to machine-readable text, braille transcriptions; and touchable objects for people who are blind or partially sighted (Figures 5 and 6). Bringing these exhibits to places or events that disabled people are likely to visit or attend, opened another way out of the same conundrum: the special town hall on accessibility, post-secondary education and employment held at Carleton University in October 2017; the annual conference of the Canadian Association For Refugee And Forced Migration Studies at Carleton University in May 2028; the annual conference of the Canadian Disability Studies Association and Social Justice Week held a Toronto Metropolitan University in May-September 2018; a course in disability studies at the University of Toronto in the following Fall, as well as the critical disability studies unit at York University; the W. Ross MacDonald School for the Blind, Brantford, Ontario, in the Winter of 2018–9. Along the way, many librarians, whose professional interests in access to documents converged with those of CUDRG, supported the exhibits personally and financially. Some welcomed the installation of *Envisioning technologies* on their premisses: Carleton University’s MacOdrum Library in January 2017, as well as the Main Branch of the Ottawa Public Library in July 2017 (Figure 6). The exhibit followed all CUDRG activities, from a “Symposium on Interdisciplinary Research, History Exhibits and Pedagogy” held in December 2017, open to all community members interested in the history of disability and devoted in part to piloting and workshopping an episode of *Envisioning technologies* on refugees, disability and technology (CUDRG, 2017a, 2017b, 2017c), to an event organised with Elections Canada in March 2018 to reflect on current and projected programs enhancing access to voting.



Figure 5: QR codes on the panels of the traveling exhibits for access to visually impaired visitors: “Two

Quick Response (QR) codes are positioned at the bottom right-hand corner. The one closest to the corner, once scanned, leads to accessible text of exhibit panels. The second code, to the immediate left of the first code, leads to the virtual version of the exhibit.” Right: Artifacts lent by the Canadian Museum of Science and Technology (CMST) as well as the Canadian National Institute for the Blind (CNIB) displayed in a safe area, in order not to be placed behind glass, and to be touchable (CUDRG, 2016a, 2016b). Design: Beth Robertson; Photo: Dominique Marshall.



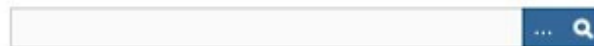
Figure 6: CUDRG member and librarian George Duimovich together with Alexandra Yarrow and Tony Westenbroek of the Ottawa Public Library, standing beside the panels and sitting area. The braille transcription, produced thanks to Richard Marsolais, CUDRG member and worker at the Canadian National Institute for the Blind is located on a low table in between the chairs for casual reading, as is a brief exhibit description (CUDRG, 2017a). Centre: The exhibit moved to Carleton University MacOdrum Library, where artifacts belonging to the New Sun Joy Maclaren Adaptive Technology Centre of the MacOdrum Library were added to those of the CMST and the CNIB. The braille transcriptions are on the high table against the wall. The objects, however, were not accessible to touch (CUDRG, 2017b). Right: The travelling panels contained the same QR codes. On this picture, they were on display at the 2017 annual conference of the Canadian Disability Studies Association (CUDRG, 2020a). Design: Beth Robertson; Photos: Sandy Barron and Beth Robertson.

To this day, virtual displays of historical documents represent the primary means used by the CUDRG to make archives of disability visible and accessible. Research assistant Dorothy Jane Smith, designer of the first virtual exhibit of the group on the wheelchair as an artifact of disability history, introduced the digital project as a way to alert non-professionals to the ways that disability is constructed out of impairment. She announced the virtual exhibit in a talk at the Accessibility Summit, held in July 2014 at Ottawa’s Convention Centre; subsequently, an e-mail campaign was sent to civil society associations working with disabled people in the region, identified with the help of CUDRG partners from the Canadian National Institute for the Blind.

A founding objective of the recent *Oral histories* project was to make the collection of interviews accessible to disabled people, through the creation of a digital exhibit of the new archives (Figure 7). The first issue that the research team addressed was to learn what accessibility entailed in this case (Williams, 2015; Nepveux, 2015). Through each step of the research process, the team’s knowledge of accessibility increased and became more refined. To ensure that the *Oral histories* would be available as broadly as possible, the interviews were transcribed. Moreover, in the preparation of the virtual exhibit, the research team began with making sure that the visual design of the material was in high contrast, and that the writing was clear and in plain language (Lundgard, *et al.*, 2019). In charge of designing the site of the *Oral histories* exhibit, Alicia Kalmanovitch reported that, as the project progressed, attention turned to issues such as making the documents accessible on

a Web site for a screen reader. Omeka, the Web-publishing platform for the display of collections used to this point by the CUDRG, was an important tool, amenable to the input of metadata, especially to provide image descriptions complying to codes of accessibility, but it was not without its challenges. Because the tool has pre-designed theme options, the user has no control over the color pallet or font size, which limited the options for enhanced access. Finally, all of the images were accompanied with written descriptions so that they can be used by screen readers (Kalmanovitch, 2022).

ACTIVISM IN THE DISABILITY RIGHTS MOVEMENT IN CANADA BETWEEN 1970 AND 2020



Browse Exhibits



Welcome to the Oral Histories of Disability Right Activists exhibit. This project is part of [Carleton University's Disability Research Group](#) and documents the oral histories of disability rights activists in Canada from 1970 to 2020. In the exhibit, you are able to watch and listen to these oral histories.

RECENTLY ADDED ITEMS

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FEATURED EXHIBIT

You have no featured exhibits.

Figure 7: Screenshot of the home page of the virtual exhibit on *Oral histories of activists in the disability rights movement in Canada (1970–2020)* soon to be launched on the Web site of the Carleton University Research Group (CUDRG, 2023); Design: Alicia Kalmanovitch.

The features of the future *Oral histories*' Web site will build on a reservoir of experiments in the accessibility of digital products conducted by the designers of the previous CUDRG exhibits. Building on the features used in the making of *Envisioning technologies* introduced earlier, the group's researcher Ryan Patterson, author of *Disability futurity: Interdisciplinary anticipations of a non-normative tomorrow* (Figure 8) (Patterson, 2021) used many devices. Patterson and the project's RAs

Sharon Smith "The Role of Risk in Relation to Special Educational Needs and Disability"



Human-dictated audio of this page.



Recorded by Sharon Smith on February 5, 2020.

For audio description, please watch this video on YouDescribe at the following link (best with Google Chrome or Mozilla Firefox): <https://youdescribe.org/video/T1Hg9lJ0wS4?ad=5ec80b6fd8088e3397699689>

Disability Futurity: Interdisciplinary Anticipations of a Non-normative Tomorrow

Dr. Claire Penketh, "Art Education and Disability Futurity: Subjects on the Edge"

Dr. Mike Gulliver, "Living as if we already know what 'human' will be: Exploring the anticipated futures of visual/deaf humanity and how they shape the present"

Seeley Quest, "Representations of Disability Experience in Live Theatre"

Figure 8: Screenshot of one of the pages of the virtual exhibit "Disability Futurity" displayed on the Web site of the CUDRG, showing several of the accessibility solutions — Design: Ryan Patterson.

put considerable effort into producing accurate video captions. We found the most robust method was to manually transcribe each seminar video into a word document, proofread this transcription, then copy and paste this transcription into YouTube's inbuilt caption function. YouTube has an auto-timing function that aligns transcription text to match speakers' timing. This is effective but not perfect, so we then edited YouTube's automatic timecoding (through YouTube's provided interface) to

make it match. An additional benefit of this method was it allowed us to offer a downloadable transcription for Web site users. We formatted these files to be easily readable for sighted users (speaker names clearly listed, spaces between paragraphs) and easily read by screen readers.

In addition to captions, the team produced a voice description of each page of the virtual exhibit. He explains their method and how they determined it:

After assessing the options available, we used the Web site YouDescribe to produce described video of all seminar recordings. YouDescribe is a non-profit project by the Smith-Kettlewell Eye Research Institute. It allows one to search for videos already on YouTube and provides an interface to record descriptions overtop of it (either pausing the video or played simultaneous with it as preferred).

On the related question of making the interviews accessible in languages other than English, Patterson's team gained some experience and insight.

Our method of fully transcribing interviews into Word files before making closed captions also made it easier to have these documents translated into French, as document translation is more cost effective than video translation. Budget limitations did prevent us from translating all the seminars into French or pursuing translation into Indigenous languages, but some translated French seminar transcripts were available for download on the Web site seminar pages. We were also able to hire an independent contractor for English-to-French translation who is deafblind (Patterson, 2022a).

Before their release many of these features were tested by disabled people from the collective. The trials and errors the CUDRG underwent in the name of "Preserving and accessing disabled heritage" resembles that of colleagues of this relatively new field who use virtual platforms who share the goal of "Making archives more accessible for disabled people" (Sawyer, 2022).



5. Producing accessible archival finding aids

The CUDRG promotion of archives in disabled communities has converged with the larger goal of Carleton's Archives and Special Collections, whose employees work with individuals on a case-by-case basis to ensure that they have optimal access to their holdings and space.

In the longer term, they aim to obtain basic accessibility for the whole consultation space, on the fifth floor of the Carleton University library. Accessibility and access to archives have been longstanding challenges because large parts of their holdings are physical, and in many different formats reflecting the nuances of inscribed information tied to a particular time, place and context (Cook, 1997). One of the ways that archivists help individuals do their archival searches is through the creation of finding aids (Society of American Archivists, n.d.; Millar, 2017). As with many heritage institutions, archives have integrated digital finding aids to increase discoverability and accessibility to their various fonds and collections (International Council of Archivists, n.d.; Artefactual, 2022). While this has greatly enhanced visibility of the holdings and allows individuals to complete searches independently, there are still inherent accessibility issues that need to be

addressed.

There is still work to be done to ensure that archival holdings are discoverable for those who need tools such as screen readers to assist them with Internet-related or other computer archival work. As an example, Access to memory (Artefactual) “is a Web-based, open-source application for standards-based archival description and access in a multilingual, multi-repository environment” (Artefactual, 2022). However, as accessibility standards evolve and our understanding of what it means to truly be accessible in the digital realm changes, there has been a push from the archival community to ensure that archival descriptions provide access for all (AIM25, *et al.*, 2018; Snider, 2014a; Library and Archives Canada, 2022).

Throughout the pandemic, as archival institutions in Canada closed their on-site access, individuals could complete their research only online through Web-based applications like AtoM. This amplified the ongoing issues that individuals with accessibility issues already faced and offered the archival advocates for accessibility an opportunity to gain further traction in pushing for better accessibility standards (Snider, 2014b; Babcock and Barber-Pin, 2020; Association of Canadian Archivists, 2017). Access is a central pillar for archivists in Canada, as stated in the Association of Canadian Archivists’ Code of Ethics: “We make records available to the widest possible audience in a manner consistent with their content, source, and the statutory obligations that govern the jurisdiction in which we work” (Association of Canadian Archivists, 2017). As an increasingly large number of jurisdictions enact accessibility legislation and standards, archival institutions will need to prioritize this work to meet ethical and public obligations.

Conclusion: Honouring the “fluctuating” nature of disability and of archives

This paper highlights the importance of being able to access disability-related resources, and specifically the value of access to archival data. Centered on our experiences with the *Oral history of disability activists* project of Carleton University we identified some of the main opportunities and challenges that we faced in creating new archival data, and preparing it for ease of access, particularly for disabled people, using online technologies. An important objective of this article is to share our experiences — both the positive aspects of them, and the challenges we faced. We hope that some of decisions we made, some issues we sidestepped, and the many small serendipities in between, will be instructive for other researchers interested in this field of work.

One of the key messages is that a lot of work remains to be done and that the process, like many areas of work, is iterative. We need to decide which data to collect, determine where to find it, find ways to collect it, refine the data itself, and make it easily accessible to others. It is a process that requires hard work and patience. It is a process of building and re-building. We learned that in the process of working on disability histories, we need to be prepared for unexpected opportunities to collect data for an archive, and for the unexpected challenges that come with them. We cannot shy away from these challenges, but rather we must remain open-minded and flexible in how to address them. We learned to accept that difficulties and setbacks may require us to revisit, refocus, refine, or reformulate our goals and purposes. Also, we learned to appreciate that new questions and new troubles can open up new learning frontiers.

We should be mindful of who we are including in our research; the phrase “nothing about us, without us,” central to critical disability studies, required revisiting throughout the project. We did this regularly in our team meetings. Working as a group was invaluable in this respect because we kept each other in check about the main goals of our project and whether we were moving in the direction of fulfilling them. Having persons with disabilities on the team, from the region and from our institution, was central to keeping this focus. Moreover, since many of the peoples with disabilities working with the CUDRG over the years have been students, faculty or staff who make up the university, they have been creating/documenting/exhibiting their own histories and futures. In this sense, CUDRG arose and evolved through a grassroots process, it was not an original and established part of the system of higher education. Among other factors, this decade old group was founded through the trusted community relations, struggles, hard work, visions and commitment of a few

very dedicated people.

We included a significant piece on the previous work of the CUDRG for the very purpose of taking stock of a multiplicity of, often haphazard, paths taken which led to the *Oral histories*. We took the time to reflect on the meaning of the documentary work of the CUDRG, in the light of the writings of colleagues who have started to examine methodically relations between archives and disability. Conversely, we hope that this reasoned introduction to the CUDRG's tentative and multiforme combinations of disability and archives will help reinforce, validate, encourage, and make explicit the work of fellow researchers, students and practitioners.

Retrospectively, we suggest that the structure and membership of the CUDRG might have helped point the team in the direction of certain topics, and of certain methods to serve these topics well, which led to "critical archival practices". Early decisions to research and display things that disabled people made, used, or tweaked; later decisions to focus on past deeds and words aimed at the recognition of the rights of disabled peoples, led to work that was not directly about people's bodily or mental abilities, or any fixed identity. It was rather about speeches, creations, and public actions. Many of the topics and methods from which the archival documents emerged called for more work — workshops, seminars, meetings, conversations, archival, library and museum trips, virtual and physical exhibits. Several choices discussed above seem to have kept our approach to disability, as well as the corresponding "configurations" of the CUDRG archives, and our idea of their potential visitors and creators, more "fluctuating", "expansive" and "imaginative" than we realised explicitly (Brilmyer, 2020).

Epilogue: The potential of the university environment

In this epilogue we elaborate on how we see the university embodying a strong potential for advancing critical disability archival research. As an institution comprised of several disciplines, in theory, the university is a "ready-made" and unique site for collaborative, collectivist work. Few institutions are able to gather under one roof: archivists, librarians, historians, engineers, psychologists, medical researchers, sociologists, doctors, and social workers, among others. Typically, each discipline has its own body of students, scholars and researchers, disciplinary traditions, resources, and community partners. Sharing various approaches to a common topic can lead to new and diverse knowledge-building and the process of collaboration that this involves can foster a strong and sustained measure of mutual learning and stability in an institution.

But although the university has this potential, there is no assurance that the cross-disciplinary research on disability issues actually will take place. In the case of Carleton University, a confluence of factors led to the development of the Carleton University Disability Research Group (CUDRG) which spearheaded the expansion of disability work on campus, and beyond. Individual champions of disability research including students, faculty and other service providers; involvement of disabled persons; interdisciplinary sharing and working with other (non-disciplinary) units in the university (*e.g.*, the archives and special collections, the library, health services); and a general political environment in the university conducive to disability research were variously involved in the success of the CUDRG. Located in Ottawa, the nation's capital, Carleton University also has the added benefit of sitting amidst a rich reserve of federal government departments, embassies, and the headquarters of several disability organizations with whom to exchange information, share ideas and resources, and build relationships that take us beyond the university community.

The interdisciplinary nature of academic work cannot be understated; it can create important new learning for students and faculty. In the case of the CUDRG, for example, Adrian Chan, an engineering professor was interested in ensuring that his students did not forget the wealth of ideas that are embedded in past traditions regarding disability issues. Chan made it his mission to seek out machines from the past and to educate his medical students on the importance of this past history, as a way of informing present and future engineering projects. By the same token, students in social work learn about the efforts that have been made in the past for assisting people with disabilities and the experiences of these people. Being able to step into the past, and eschew preconceived notions of how things were, is a valuable experience for all of us. As Jennissen and


Lundy's work on radical female social work has shown, history is important for understanding more about past strategies used by radical social workers to work for positive social change and to challenge the policies and practices that disadvantage many people (Jennissen and Lundy, 2018).

A general role of the university is to advance knowledge. This involves research, enquiry, questioning, and pushing the frontiers of what we know and do. Because this is the mission of the university, we are somewhat less encumbered than other institutions (governments for example) by the demands pre-existing guidelines for conformity. That is, we are relatively free to explore new avenues which may not exist in other institutional contexts.

Although technology has changed modes of access to data sources, the library and by extension, archives and special collection, continue to play a paramount role in the university generally. The Archives and Special Collections (ASC) unit and the library at large at Carleton University, specifically, have had a central role to play in providing a safe and enduring place to safeguard disability heritage, and ensuring that the documents in its possession are accessible to everyone, with particular attention paid to accessibility for people with disabilities. Too often we find that the records may be there, but they are not accessible. Having an archivist knowledgeable about disability issues on our research team at the outset, gave us confidence that the goals of the project would be met.

Research in universities is supported by funding infrastructures as well as support to access funding outside of the university. These avenues for financial support are important for any type of research, and in our case, it gave us the opportunity to hire research assistants and a disability consultant that were essential for our project. Our research team on the *Oral histories* project was given multiple training opportunities of which they took full advantage. It was also important that we were providing employment to our students.

One of the major benefits of our place of work at the university is that it puts us in contact with younger generations of students who are in the process of developing research careers. Working across generations is one of the most fruitful experiences of academic work. Students bring forward fresh ideas, untested perspectives, their own experiences, and optimism for the future. We witnessed this regularly in our group as the team members offered suggestions; took on opportunities for learning more about the technology; the processes of interviewing; and presenting their work. The research team members were strong champions of the *Oral histories* project. Connecting emerging researchers with veteran activists was an educational experience for the whole research team.

The development of disability-related histories is an important part of the work required for “enacting political change now” (Brilmyer, 2022). Building archives for the preservation of disability history, in fact, is a form of political activism; our team was aware of this and glad to participate in that process. 

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Note

1. Adams, *et al.*, 2015, p. 5; Brilmyer, 2020.

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