**Invitation to Participate Letter and Consent Agreement: Self-Employed Individual**

You are invited to participate in a research interview because you are *a person with a physical disability who is presently self-employed in either a permanent, full-time position; or in a long-term, remunerative position that allows you to be financially independent. We would like to talk to people with disabilities who have successfully navigated the challenges of finding and maintaining gainful self-employment.*

Over the course of the project, we will gather a diversity of lived experience stories from disabled workers/employees from different cultures, races, backgrounds and countries. From these discussions, we hope to gain understanding of workplace successes and challenges for people with disabilities in different jurisdictions. By exploring the insights of disabled persons who secure and maintain employment, the research findings may improve recruitment and retention of persons with disabilities, improve workplace culture, and promote more inclusion in the workforce overall.

**The PROUD Project Study Team**

Principal investigator: Dr. Chloë G. K. Atkins, Associate Professor, Department of Political Science, Scarborough College, University of Toronto

Co-investigator: Dr. Andrea Whiteley, Postdoctoral Fellow, Department of Political Science, Scarborough College, University of Toronto

**Project Description**

This interview is part of a research project funded jointly by the Social Sciences and Humanities Research Council (SSHRC) and the [Department of National Defence Research Initiative](https://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/dnd-eng.aspx) [https://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/dnd-eng.aspx].The project aims to enrich the discussion of employment and disability by moving beyond the collection and assessment of dismal quantitative data. Consistently, research clearly outlines the extraordinary difficulty disabled adults have in obtaining and maintaining full-time, gainful employment, despite legislation that supports workplace accommodations and inclusion.[[1]](#footnote-1)

The project compares several countries (Canada, U.S., Britain, France and Belgium), and focuses on “what works” for adult disabled populations. In studying individual experience, or micro-level challenges and successes, we are interviewing three different populations: (i) employees and self-employed individuals with physical disabilities, (ii) able-bodied coworkers who work beside people with disabilities, and (iii) employers. The goals of this research are to improve employer hiring practices; improve the employment experiences and labour environment for people with disabilities; and encourage diversity in employment and entrepreneurial sectors in Canada and around the world, *by focusing on what individuals, organizations and governments are doing right*. The research results will contribute to best practices and develop policy guidelines to promote better approaches to disabled recruits and to improve the treatment and engagement of disabled persons in labour forces.

**Nature of Participation**

You will be interviewed about your experiences in the workforce as a person with a physical disability. Your interview will take no longer than one hour at a location of your choice and employing technology that is both available and accessible to you. We will be using secure, virtual conferencing technology to conduct interviews. You can consent to either audio or audio and video interface. Interviews will investigate your employment experiences and may address the following topics: your job searches, your day to day experiences on the job, referring to your present place of employment or previous jobs you may have had; your challenges and successes regarding your employment; what kinds of accommodations are required for you to work; whether you have experienced any feeling of bias or discrimination in the workplace; suggestions you might have to help other people with disabilities navigate and thrive in the workforce.

Other questions and topics may come up during the interview, with a focus on your unique experiences and perspective.

All interviews will be conducted employing secure, virtual conferencing technology. We will ensure that the technology is available and accessible to you. The University of Toronto employs Microsoft Teams as its primary mode of conducting such exchanges. It requires that every participant download and use the Microsoft Teams application. It is important to understand that while Microsoft Teams is a familiar technology, it is not totally secure. Nonetheless, the likelihood of a security breach is small when using Microsoft Teams and it more easily allows for secure recording of the interviews.

The interview will be recorded. The audio recording will be securely transcribed and summarized by the researchers. If possible, we might ask to take photos of your workplace accommodations, but will do so only with permission (see consent below). These photos will only be used by the researchers to document workplace accommodations and will not be publicly available, so as to protect the privacy of you and your workspace. After the interview, you will receive a copy of the transcribed interview and a summary by email so that you have the opportunity to withdraw, amend or further elaborate on your comments. At the end of the project, the research results will be shared with all participants in an executive summary and full report. If you are interested, you will also be invited to participate in a knowledge mobilization event that draws together research participants, scholars, employers and policy makers to discuss the research conclusions.

**Confidentiality**

Your participation in this project will remain confidential and private identifying information will not be shared with the public, unless you indicate otherwise after the interview -- see below. Only the study team and the University of Toronto Research Ethics Program will have access to your contact information, the audio files and transcripts of the interview. The interview will be audio recorded, transcribed by a secure transcription service, and data that might identify participants (e.g. name or organization) will be removed from the transcripts. Audio files and transcripts of interviews will be stored on secure servers and computers at the University of Toronto, and on researchers’ password protected and data encrypted computers and equipment. Any files with personal identifying information will be kept for the duration of the project and then destroyed. If any secondary use of an audio file is required e.g. for another project, the researchers will seek separate, individual consent to use an audio clip. There are presently no plans to use the audio files beyond this project.

Please note that the University of Toronto Research Ethics Program may have confidential access to this project’s research data to help ensure participant protection procedures are followed. The following link provides further detail about the university of Toronto’s informed consent policy and ethics requirements:

<https://research.utoronto.ca/informed-consent>

Some participants may want their name or organization known. You will have an option at the end of the interview (or at any time during the study) to disclose your name and/or organization.

Any demographic information gathered will only be used for understanding our research participants, and reporting on research results. All participants will be identified only by an identifier code and will not be identified by name in any reporting of the research results (unless the participant wishes to be identified). University of Toronto Information Technology services stores data in Canada, and is compliant with the Freedom of Information and Protection of Privacy Act (FIPPA).

**Risks and Benefits**

Our study involves individual, confidential interviews about your lived experiences in the workplace, but due to the sensitive and personal nature of the interview process, participants might have feelings of anxiety or stress recounting personal, emotional or traumatic experiences in the past. To mitigate this psychological risk to participation, the research team has a protocol for dealing with stressful situations. If during the interview you feel severe emotional stress, the research team will offer moral support and options to mitigate the stress such as allowing participants to pause, take a break, or exit the interview if required. Dr. Atkins has a physical disability and can empathize with the interviewee. Before commencing, the researchers will remind you that you may decline to answer any questions or discontinue the interview at any time without fear of penalty.

There are some limits to confidentiality associated with individuals’ roles, expertise, locations or disabilities where our reporting research results could result in a person being identified —e.g., if there might only be a relatively small number of individuals with the roles, expertise, locations or disabilities in question. We will do our best to mask individual identity by using general descriptions about your place of work and geographic location.

We would like to document your work space with photos (if possible). This is not a requirement for your participation, however. Any photos of work spaces or accommodations will only be used by the researchers for analysis and not shared with people outside our research team. For any external reporting on the research, such as in journal articles, our website, or conference presentations, we will discuss participants’ accommodations textually or use stock digital images. We are interested in having photos because understanding the physical workspace needs of workers with disabilities may contribute to a better understanding among employers and policy makers about what works best.

The researchers intend to share the research results with participants, employers, policy makers, funders, governments and the public. The research outcomes could contribute to better working conditions for people with physical disabilities, improved hiring practices for employers, a more positive and inclusive labour environment for people living with disabilities who want to be employed, and improved public understanding of people living with disabilities, their challenges and needs. This potential benefit is the primary motivation for carrying out the study, and the researchers are transparent about pursuing actionable research outcomes (if some might consider this a bias).

There are no other known physical, social or legal risks to participating in this project.

**Compensation**

If you consent to participate in the interview, you will receive a $50 gift card to thank-you for sharing your experiences. You will also be reimbursed for transit or parking expenses if applicable. The researchers will also cover special costs associated with the interview such as requiring a sign language interpreter or another accommodation to make the interview possible.

**Conflicts of Interest**

There are no known conflicts of interest for the researchers. Dr. Atkins has a chronic illness and is disabled. She has experienced the precarious nature of employment throughout her career. As such, Dr. Atkins has a personal connection to the study’s focus.

**Protection and Future Use of Participant Data**

Results from this study will be disseminated in many different ways. Research findings will be reported back to participants and to the stakeholder community in research journals articles, presentations to stakeholders and other interested parties, disseminated to the media in opinion/editorial articles (Op/Ed), or published reports on research in the mainstream media such as newspapers and blogs.

The interview data (audio files and transcripts of the interviews), however, will not be made open or shared outside the project due to the sensitive nature of the subject and the need to protect confidentiality. All data gathered during the project will be protected according to University of Toronto’s data security and encryption standards available at:

<https://research.utoronto.ca/data-security-standards-personally-identifiable-other-confidential-data-research>. For example, audio recordings will be made on a password protected and encrypted cell phone or recording device, but deleted after the files are transferred to a secure server environment. After the project is finished, the research data will be kept for five years, after which time it will be deleted from computers and/or paper copies securely destroyed.

Any paper copies of documents containing personal identifying information e.g. researcher notes, will be stored in a locked office and locked cabinet. The signed copy of this consent form will be kept in a locked cabinet for five years after which time it will be shredded.

**Voluntary Participation and Withdrawal**

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may decline to answer questions, discontinue the interview, or choose to withdraw from the study at any time without any fear of penalty. If you wish to withdraw your participation after the interview has taken place, please contact the researchers by email. Your data will be removed from the study and all audio recordings and transcripts will be securely destroyed.

**Contact Information About the Study**

Please contact Chloe Atkins at chloegk.atkins@utoronto.ca or Andrea Whiteley at andrea.whiteley@utoronto.ca

**Contact for Complaints**

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273

**Consent and Signature Page**

Please indicate your agreement to participate in the study by checking the following boxes and providing your name, date and signature below.

I have read the consent agreement and agree with the details of my involvement in this research project.



The researcher (Dr. Atkins or Dr. Whiteley) has gone over the consent agreement and answered any questions.



PLEASE CHOOSE ONE of the TWO FOLLOWING OPTIONS:

I am comfortable with, and agree, to have our research interview being audio recorded. I do NOT consent to video recording

OR

I am comfortable with, and agree, to have our research interview audio and video recorded.





I consent to provide photographs of my workplace.



I have received a copy of the consent agreement for my records.



I have received a $50 gift card to thank me for participating.

Participant Signature Date

Participant Name Witness

**Consent for Photography of Work Spaces**

This separate consent is to allow the researchers to document your work space and any physical accommodations you might need at your place of employment for research analysis purposes, and not for public view.

I am comfortable with and agree to have my work space accommodations documented using photos. 



I have the authorization of my organization to allow for the documentation of work spaces.

Participant Signature Date

Participant Name Witness

**Consent for Disclosure of Name of Participant**

Now that the interview is complete, are you interested in having your name or organization appear in subsequent research reporting?  If you agree with being named in the research reporting as a participant, please sign the consent form below.

I am comfortable with and agree to have my name mentioned in reporting for this research project. 

Participant Signature Date

Participant Name Witness

1. United States Census Bureau: [Do People with Disabilities Earn Equal Pay](https://www.census.gov/library/stories/2019/03/do-people-with-disabilities-earn-equal-pay.html); [The Conversation: Employers Miss Out on Talent By Overlooking People with Disabilities](http://theconversation.com/employers-miss-out-on-talent-by-overlooking-workers-living-with-disabilities-119626) [↑](#footnote-ref-1)