



UNIVERSITY  
OF MANITOBA

## Faculty of Education

Hello,

We are professors and researchers at the University of Manitoba. We are interested in learning more about how human rights affect the lives of adults with intellectual disabilities. When we talk about adults, we mean individuals who are 18 years of age and over. Our study is called: “Human rights and people with intellectual disabilities: Perspectives of family members and support providers”.

In order to conduct our research, we are looking to recruit up to 20 people who have an adult family member with an intellectual disability to participate in two focus groups. We anticipate that the focus group will take about 2 hours of your time. We will hold focus groups at the Millennium Library in downtown Winnipeg or a similar venue that is accessible by public transport and has ample parking facilities.

Before the focus group begins, we will distribute a consent form for you to read, consider and sign. We will go over this form with everyone before we begin the focus group itself. If you have any questions during that time, we will do our best to address your questions and/or concerns. We will audio-tape record the focus groups and later transcribe what was said verbatim. We will also take written notes. These notes will help us to recall the discussion and also serve as a back-up in case the digital recording malfunctions or is inaudible in any way. These notes will be incorporated in our analysis if and as necessary. As well, we will have someone capturing the discussion in images, which is known as graphic recording. This helps us to capture the “big ideas” of the conversation and also serves as a checking tool so we can ensure we have accurately understood your comments.

Your confidentiality will be maintained, as we will not refer to you by name. We will assign you a pseudonym. We will also refrain from identifying any organizations, groups or individuals you may mention during the course of the focus group by omitting the reference or assigning a pseudonym. This means that we (the research team and graphic facilitator) will not share any information from this session with anyone else. We also insist that you not share the names of your fellow participants or what was discussed during the focus group with anyone else at any time. However, because we have no control over who might say what outside of this group, we cannot promise you complete confidentiality.

If you choose to participate in this study, you may refuse to answer any questions, leave the session, or withdraw from the study completely at any time. In consideration for your involvement, you will be given a \$25.00 honorarium. You may keep this honorarium, even if you choose to withdraw from the study. Please note that if you withdraw from the session part way through the discussion, we may not be able to delete everything you said during the discussion if we have difficulty in identifying your voice when we transcribe the audio recording.

After the research is complete, we will send you a summary of our findings.

The results of this study will become a chapter in a book on people with intellectual disabilities and human rights in the Manitoba context. A proposal for this book has been submitted to the Centre for Human Rights Research, University of Manitoba and has received a favourable response. Each chapter of the book will contain a plain language summary so the results of this study will be accessible to people with intellectual disabilities. We will also actively seek forums to present our findings to local organizations supporting individuals with intellectual disabilities such as People First and Community Living. When study results are shared, all findings will be presented in a way that does not identify any participants.

The only people who will have access to the raw data with identifying information will be the Principal Investigator, co-investigator and a student hired to assist with the research project. Raw electronic data will be stored on the encrypted drive in a locked drawer in the office of the PI for a period of at least five years, as it is anticipated that this pilot study will lead to a more comprehensive study and the researchers may wish to access the raw data from this study in conducting the future study. Once the larger study has been completed, transcripts and notes will be destroyed. The electronic data will be erased (wiped clean) from the digital storage device. Hard copy data will be deposited in the “Shred it” container in the Faculty of Education for professional shredding.

We do not anticipate more than minimal risks to participants as a result of participating in this study. We will explain before the focus groups begins that should anyone feel uncomfortable during a session, he or she is free to leave the session at any time or simply listen to the conversation and not actively participate. We will also explain that there is no penalty if anyone decides not to participate or to leave the session. However, participants may feel this kind of discussion is relevant to them and important to have. There is a lot of discussion in Canada and internationally about human rights and about rights for people with disabilities in particular. These focus group sessions will give participants the opportunity to talk about their experiences with human rights for adults with intellectual disabilities.

This research has been approved by the Education Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact the researchers or Maggie Bowman at the Human Ethics Secretariat at 474-7122 ([Margaret.bowman@umanitoba.ca](mailto:Margaret.bowman@umanitoba.ca)). A copy of this consent form has been given to you to keep for your records and reference.

We are planning to have the focus groups in late summer and/or fall. If you want more information or if you would like to take part in a focus group, you can e-mail us or call us. Our contact information is at the end of this letter.

Thank you,

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