

 School of Social Work, Fredericton, NB CANADA E3B 5G3

**housing needs and preferences**

**You are being asked to participate in a research study. Before you decide, it is important that you read the following information and ask as many questions as you want so that you are clear what will be asked of you.**

***What is the research about?***

The proposed research is about the housing needs and preferences of people living with developmental disabilities in the Greater Fredericton area. We are interested in your current and future housing options, and related matters.

***Who is conducting the research?***

Dr. Clive Baldwin and Michelle Greason are leading the research. Dr Baldwin is Canada Research Chair in Narrative Studies at St Thomas University (STU), and Michelle Greason is a Research Associate of the Centre for Interdisciplinary Research on Narrative at STU. The research in being conducted for Willow Tree Inc, a not-for-profit agency working with adults with developmental disabilities and their families. The project is funded from a grant from the Fredericton Community Living Foundation. The research has been approved by the Research Ethics Board of STU.

***Why have I been invited to participate?***

You have been invited to participate because you identify as having a developmental disability or are a carer of someone with a developmental disability.

***If I am interested in participating, what should I do?***

If you are interested in participating, please contact me, indicating your interest and asking any questions you might have. You can do this by phone, e-mail, or regular mail:

Dr. Clive Baldwin/Ms Michelle Greason,

Rm 313, Brian Mulroney Hall

St Thomas University, Fredericton, NB

Canada E3B 5G3

Phone: 506.452.9596
Email: baldwin@stu.ca

hdwjw@stu.ca

***What does participating in the research involve?***

In agreeing to participate in the research you are agreeing to take part in an interview of approximately 1 - 1 ½ hours in length. In the interview you will be asked about your experiences of receiving and/or giving care, your housing and related activities, and your wishes for th e future. You will be able to tell us about your experiences in as much detail as you want.

Ideally we would like to interview you in person and interviews would be arranged at a time and place convenient to you and are quite informal. Any out of pocket expenses (e.g. travel costs) will be reimbursed.

If a face-to-face interview is not possible due to geographical location and/or costs we may ask to interview you by Skype or telephone. You will be asked for your permission for the interviews to be recorded. If you would like to see the transcripts of your interviews prior to giving permission for their use, we will send these to you.

We will also ask you for a small amount of personal information (for example, age, gender) that will help in the research – all of which will be kept completely separate from the interview material.

***What will happen to the information I provide?***

Interviews will be typed word for word (transcribed) and all information that could identify you (e.g. names, places, dates etc.) will be removed. The information will then be analysed and used in reports, journal articles, conference presentations and educational materials. All information will be edited so as to ensure that you cannot be identified.

All information will be stored in locked filing cabinets and/or password protected computer files. All material will be destroyed two years following c ompletion of the research.

***Will the information I give be confidential?***

Yes. Only those directly involved in the research will have access to the information you give us. Transcribers will be required to sign confidentiality agreements. All information will be treated in confidence, unless you disclose during the interview any previously unknown or future illegal activities and/or express a desire to harm yourself or others.

All identifying information will be removed from the information you give us. If you so wish we can send you a copy of the transcript for correction and approval before it is included in the research.

***What are the benefits of participating in the research?***

While some people find it helpful to talk about their experiences, there will not necessarily be any direct benefits to you individually as a result of participating in the research. The purpose of the research is to find out about the housing needs and preferences of people with developmental disabilities, which will then inform plans for service provision.

***What are the risks of participating in the research?***

The risks of participating in the research are minimal. It is possible that some people might become upset when recounting particularly difficult experiences. If this happens the interviewer will stop the interview until you are ready to continue or decide not to continue. You will be offered the opportunity to discuss this with the interviewer and the interviewer will help you access other resources if you would like.

***Can I change my mind? And what will happen if I do?***

You are free to withdraw at any stage without having to give a reason. If you decide to withdraw then all information you have supplied and can be attributed to you will be destroyed.

***Will I be able to see the outcomes of the research?***

Yes, you can ask to be put on the list to be sent a summary when it is available. When the research is completed a report will be available on the website.

If you would like to receive a summary of the findings of the research, please tell the interviewer. This will be sent to you following completion of the project.

***Who do I contact if I have a question or want further information?***

Please feel free to contact us by letter, phone or email.

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If you have questions regarding your rights as a participant in this study, you may contact the Chair of the St. Thomas University Research Ethics Board, reb@stu.ca

If during your participation you have any concerns about the conduct of the research or want to make a complaint, please address these, in the first instance, with myself. If you are not satisfied with the response, you may contact:

Chair

Research Ethics Board

reb@stu.ca