

# THE EXPERIENCE OF B.I.I.D./TRANSABLEISM

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 experience of people who define themselves as transabled/live with B.I.I.D. We are interested in what it is like for transabled people, their thoughts, feelings, desires, hopes, stories, relationships – indeed any and all aspects of their lives which they are willing to share. It is hoped that the research will promote understanding and awareness of transableism.

#### Who is conducting the research?

Dr. Clive Baldwin is leading the research. He is Professor of Social Work at St Thomas University (STU). 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 define yourself as transabled/live with B.I.I.D.

#### 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, Rm 313, Brian Mulroney Hall St Thomas University, Fredericton, NB Canada E3B 5G3 Phone: 506.452.9596 Email: <u>baldwin@stu.ca</u>

REB2018-05

# What does participating in the research involve?

In agreeing to participate in the research you are agreeing to take part in three interviews, each of approximately 1 ½ - 2 hours in length. The first interview will focus on your experience from the time you first began to see yourself as transabled and you will be able to tell your story in as much detail as you want. The second and third interviews will focus on clarifying and expanding on matters arising therein and on exploring particular aspects of your experience such as relationships with professionals, family and friends and what you have found helpful and unhelpful, and social and cultural issues.

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.

In addition, you may be asked whether you would be willing for a researcher to visit you and spend up to five days with you talking about and observing your daily life. This is entirely voluntary and you can still participate in the interviews even if you do not want to participate in this part of the research.

We will also ask you for a small amount of personal information (for example, age, gender, ethnicity))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 identifying personal information 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 (with the exception of audio and/or video recordings – see below).

All information will be stored in locked filing cabinets and/or password protected computer files. All material will be destroyed after seven years following completion 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 told us about another person being harmed or at risk of being harmed or about an unresolved or future crime.

All identifying information will be removed from the information you give us. You will be sent a copy of the transcript for correction and approval before it is included in the research.

In addition to being asked to agree to being interviewed you will be asked also whether you agree to any audio and/or video recordings being used in conference presentations, for educational purposes, in academic publications or in interim and final reports on the website. *This consent is entirely separate from agreeing to participate in the research and you can still participate in the research even if you do not want the audio/video recordings to be used in this way*. If you agree to these uses of the audio/video recordings we cannot guarantee that you will not be identified from the recording so please think very carefully about this. Once again, you do not have to agree to this– we can work with the typed transcripts alone.

### 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 help promote awareness and understanding of the issues facing transabled people.

### 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.

As the project is quite a lengthy one, updates will appear on the website. If you do not have access to the Internet and want to receive these updates, please let us know.

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

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

Dr. Clive Baldwin Rm 313, Brian Mulroney Hall St Thomas University, Fredericton, NB Canada E3B 5G3 Phone: 506.452.9596 Email: <u>baldwin@stu.ca</u>

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

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:

> Vice-Chair Research Ethics Board reb@stu.ca