ISAAC Policy for Recruiting Participants for Research via the ISAAC Membership Email List

Introduction

The ISAAC Executive Board (EB) receives frequent requests from researchers intending to recruit participants for their research project via the ISAAC membership address list. ISAAC promotes relevant and ethical research in the field of AAC. As such, ISAAC does endeavour to assist researchers as well as potential participants to be able to connect for mutual benefit.

However, ISAAC is not an ethical review body, and as such does not have the capacity to provide ethics approval for any potential study. The decision to take part in a study remains the choice of the individual ISAAC members.

In order to ensure that the ISAAC membership can make informed decisions about their participation, ISAAC therefore expects researchers to operate within a set of principles and parameters within which ISAAC is willing to assist them with recruitment. [Click here – see 'for researchers' below]

Equally, ISAAC would like to encourage its members to make informed choices about their participation in research. [Click here for more information – see 'for members' below]

ISAAC reserves the right to not advertise studies for which there is not clear evidence in the application that the project aligns with ISAAC's goals, mission, and/or vision and will not enter into correspondence regarding the decision.

If an ISAAC member has concerns/complaints/questions about the research:

1. Contact study investigators and/or the institute that approved the project.
2. ISAAC also welcomes notification of any concerns and will suspend advertising if received, until researchers can provide a letter from the relevant ethics committee that this has been resolved.

FOR RESEARCHERS: CONDITIONS UNDER WHICH ISAAC WILL PROVIDE ASSISTANCE:

ISAAC will pass on a brief email composed by researchers to the ISAAC membership that includes the following (based on Bryen, 2016):

1. A brief description of the research in Plain Language (max 200 words) which consist of the following:
    a. What is this study about? (max 25 words)
    b. Who can be involved? (eligibility criteria; a clear indication of who is invited to consider taking part)
    c. What would I be asked to do? (e.g., a survey, an interview)
    d. Who has approved the research (the name of the committee)
2. A link to obtain more information about the study, which contains the following:

a. A description of the study in Plain Language. The purpose, rationale, study procedures and tools/measures to be used should be clearly described. Funding sources should be acknowledged;
b. A detailed description of what will be expected from participants, including risks and benefits, protection of privacy, and a description of the way in which data will be stored and disseminated; and that participants are able to withdraw at any time without any negative consequences;
c. Official proof of ethics approval of the study by the relevant oversight body (e.g. the institutional review board) with relevant contact details (email, telephone number) to this body provided;
d. A consent form in Plain Language that can be signed online.

It must be evident from the information provided that the researcher will abide by relevant ethical principles. While ISAAC acknowledges that different requirements are relevant for different contexts, the principles of respect for persons, beneficence and justice as set out in the Belmont report (Department of Health Education and Welfare, 1979) are expected to be adhered to at all times. The researcher should also take additional precautions to meet ethical obligations towards participants from vulnerable populations. For relevant guidelines, the following documents can be consulted:

World Health Organization Guidance for Ethics Review of Health-Related Research with Human Participants:
https://apps.who.int/iris/bitstream/handle/10665/44783/9789241502948_eng.pdf;jsessionid=71A33D13BFA2CDA39FD27B219372911C?sequence=1

World Medical Association: Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects:
https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

Department of Health Education and Welfare. (1979). The Belmont Report.
https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf

Bryen, D. N. (2016). Ethical issues in conducting research involving persons with disability: A view from the past and some new challenges. *Humanities and Social Sciences, 4*(2–1), 53–59.
https://doi.org/10.11648/j.hss.s.2016040201.18

FOR MEMBERS: DECIDING IF YOU WANT TO TAKE PART IN A STUDY OR NOT

ISAAC may from time to time send out an invitation from a researcher, inviting you to take part in a study. To help you make a decision, think of the following:

- Is it clear that the research project has been approved by an Ethics Review Board? There must be a letter from the board. There should also be contact details of the board.
- You have a right to:
  - be informed of all aspects of the study and understand what participation will involve
  - not feel coerced/pressured
  - withdraw at any time – a right to ask researchers to destroy any information or allow them to keep the information already obtained

- choose not to answer a question if you do not want to
- privacy
- access the results of the study
- understand the purpose of research and its relevance; how it will help you or others
- have any questions about the research answered before you choose to take part. You can ask the researcher and/or the Ethics Review Board

Remember that it is your responsibility to make sure you are fully informed about the research before making a decision to take part. Ask questions so that you can tell if a study is the RIGHT research study for YOU. Even if you agree to participate, you can always change your mind.

For guidelines, the following document can be consulted: Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans: https://www.queensu.ca/urs/sites/webpublish.queensu.ca.urswww/files/files/HSREB/2018/CAREB%20Brochure%202017DEC21.pdf

APPENDIX A

Several of the following paragraphs are from the pre-print version *of Ethical issues in conducting research involving persons with disabilities: A view from the past and some new challenges*, by *Bryen, D.N. (2016)* published in *Ethical sensitivity: A multidisciplinary approach: Humanities and social sciences, 4(2-1): 53-59.* This article is freely available on-line:

http://www.sciencepublishinggroup.com/journal/paperinfo?journalid=208&doi=10.11648/j.hss.s.2016040201.18

Abstract

This article traces the history of conducting research involving people with disabilities and raises serious questions about the ethics of conducting research. Ethical concerns include treatment of vulnerable populations, lack of informed consent, and benefit versus undue hardship when using people with disabilities as subject of research. New technological advances, such as discussions on social media, present come new ethical concerns. Two case studies are presented that illustrate new ethical challenges. Guidelines are proposed that address the right to privacy, anonymity and confidentiality.

Ethics in Disability Research

The Nuremberg Code in 1947, the Helsinki Declaration in 1964, and the Belmont Report in 1985 form that basis of all US research regulations implemented by the Department of Health and Human Services (DHHS), the Federal Drug Administration, and the Department of Education (Research, 2011). Special protections under DHHS regulations focus on three "vulnerable" populations: (1) fetuses, pregnant women, and human *in vitro* fertilization; (2) prisoners; and (3) children. Note that individuals with disabilities are NOT included as

needing special protections in research based on being a “vulnerable” population. As such, this is one of the major problems with research ethics in the United States. It may account for the more recent violations of the Nuremberg Code (need for informed consent, knowingly harming research subjects by deliberately infecting them). Furthermore, unethical research using subjects with disabilities continues even with Institutional Review Board (IRB) oversight (Research, 2011).

When people with disabilities are stigmatized and isolated, there is a great risk that they will be viewed as less than human (Keefer, 2011). As such, the regulations that guide research practices may be overlooked by researchers. In response to this problem, Dr. Anne Good of the National Disability Authority has published an important paper entitled “Ethics in Disability Research (2005).” Based on the United Nations standards on the Equalization of Opportunities for Persons with Disabilities (1993) and the 1996 report of the Irish Commission on the Status of People with Disabilities, Good suggests the following ethical guidelines focused specifically on research involving persons with disabilities:

- “Respect for the human rights, dignity, equality and diversity of all those involved in the research process
- Advancement of social justice for people with disabilities within the wider community
- Promotion of the well-being of those participating, involved in or affected by the research process
- Avoidance of harm to those involved in the research process or to the wider community
- Facilitation of the participation of people with disabilities in research and research dissemination, including those for whom obstacles might make such participation difficult without additional support
- Maintenance of the highest professional, legal and ethical standards and competencies
- Comprehension and fulfilment of relevant legal responsibilities (2005, p. 2-3)”.

These 7 guidelines are then translated into 5 research practices that should ensure ethical research:

- Well-being and avoidance of harm
- Collaboration with people with disabilities in conducting research
- Consent: Informed and voluntary
- Respect for participants: Dignity, anonymity, and Privacy, and
- Equality and diversity among people included in the research design and planning

Farrelly (2004) provides additional requirements regarding ethical research practices involving people with disabilities. Two of these requirements are summarized below.

***Recruitment*.** In order to ensure that potential research participants understand that they do not have to participate in a study, clearly state using Easy English[1] that participation is voluntary. Tell them that they do not have to give a reason for declining to participate, and that declining will not interfere with their treatment or services. Finally, state that they can withdraw from the research at any time.

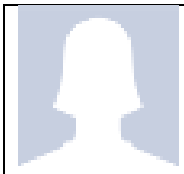
Consent. In order to ensure voluntary and informed consent, the researcher must provide a simple description of the purpose and the procedures of study. Furthermore, the researcher should explain simply and clearly how the study will benefit the individual, the length and location of the study procedures, and any adverse effects which might occur. Additional information must include what will happen with the results of the research, how and when the person will get a summary of the results, how confidentiality will be ensured, and assurance that the person can withdraw at any time. Finally, the individual giving consent and the researcher should both sign the consent form and keep a copy. An example of a consent form using Easy English with pictures is shown in Figure 1.

Figure 1. Sample Consent Form Using Easy English and Pictures[2]

scope
Disability Means Possibility

TEMPLE UNIVERSITY®

Information for Sally Joe



My name is Diane and I would like you be part of my project.

My project is to find out more about making friends and communication

[1] u more accessible style of English for people who have difficulty reading and en information. It uses clear and simple language, one idea per sentence, short sentences, direct language (readers are addressed as "you", pictures or photographs to add meaning to the text, and minimum punctuation (Victoria Department of Justice, 2011).

[2] This sample consent form is based on the work of Hilary Johnson of the SCOPE Centre in Melbourne, Australia. Used with permission.

I want to spend time with you

I want to be with you at home

I want to go out with you

I want to take your photo.

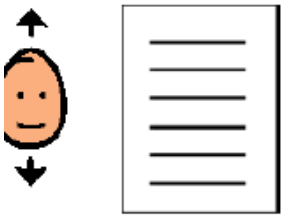
I will only use your picture if you say **yes**

What happens with your information?

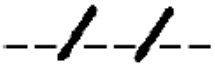
- I will keep this in a safe place for 7 years.
- I will not use your name or other information that shows who you are.

You can say **no** and stop at any time.

When I have finished, I will say goodbye.



I say yes to the information in this form.



The date today. Write the day, month and year.

_____

My name

_____

My signature

_____

OR

You can ask a person to sign for you.

The person must be legally allowed to sign for you. This person is called your representative.

Turn the page.

Representative name

_____

Representative's signature

_____

Also, a witness must sign this form.


Witness name

_____


Witness signature

_____