



NATIONAL GUIDELINES

No: G507

**RESEARCH WITHIN THE
BROTHERS OF CHARITY
SERVICES**

May 2007

**NATIONAL GUIDELINE
ON
RESEARCH WITHIN THE
BROTHERS OF CHARITY SERVICES**

Signed:

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Date:

May 2007

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INTRODUCTION

The Brothers of Charity Services, as the largest service in the intellectual disability services sector, encourages and promotes the undertaking of research by its staff and external researchers. These guidelines outline the principles under which research is carried out within the service.

“Scientific research is a systematic, controlled, empirical and critical investigation of natural phenomena guided by theory and hypotheses about the presumed relations among such phenomena.” (Kerlinger, 1986, p.10)

Research can involve the evaluation of a new practice or intervention; behavioural observations of people in natural settings; survey based research; participant interviews; and collecting data to compare effectiveness or efficacy of intervention methods (Emerson, Hatton, Thompson, & Parmenter, 2004).

All research must conform to accepted scientific principles. The National Disability Authority has produced “Guidelines for including people with disabilities in research (2002)”; “*Ask Me – Guidelines for effective consultation with people with disabilities*” and “*Ethics in Disability Research (2005)*”. These documents should be referred to prior to undertaking research.

The Brothers of Charity Services understands ethics to be, “*the study of morals and values: that is, the study of right and wrong, justice and injustice, virtue and vice, good and bad, and related concepts and principles*” (National Health and Medical Research Council, 1999, p.63).

Ethical issues should not be confused with methodological ones. It is quite possible to conduct a study that uses reliable data collection methods and produces important findings but which may raise ethical concerns. Conversely, it is equally possible to conduct a study based upon the highest ethical standards that is methodologically flawed and contributes very little by way of useful findings as a result (Connolly, 2003).

KEY PRINCIPLES

The key principles under which research is undertaken within the services of the Brothers of Charity are as follows.

- Respect the dignity and autonomy of the individual and ensure, in relation to the research process, the physical, social and psychological well-being of all those who participate in research studies or are subsequently affected by the findings.
- Insure that each individual's informed consent is obtained prior to any involvement in the research process. If a service user is unable to consent, a substitute decision maker (proxy) will be asked to give consent. The ability of a person to provide proxy consent will depend on the status of legislation or other legal guidelines and the nature of the research being proposed (National Health and Medical Research Council, 1999).
- Use various forms of communication to ensure that individuals have an opportunity to participate in the research process. According to Kitchin (2000) who recorded the views of a sample of persons with a disability: *"the ideal model [of research] forwarded by respondents was one of inclusivity: an equal-based, democratic, partnership between disabled people and disabled/non-disabled academics"* (p.45).
- Have a system that can record and recognise non verbal communication indicators of desire to participate or not to participate.
- Equalise opportunities by ensuring that no discrimination takes place for example having material available in accessible formats to enhance equality of participation.
- Ensure that the individuals involved have an opportunity to direct or take part in the whole research process.
- Promote the rights of participants and encourage organisations and researchers to undertake to do the same.
- Ensure that ethical practice is an integral part of the planning and methodology of research.

CODES OF PRACTICE AND LEGISLATION

It is the policy of the Brothers of Charity Services that all those undertaking research within the Service will adhere to the requirements for the protection of data and information under the Data Protection Acts (1988; 2003) and Freedom of Information Acts (1997; 2003). In addition, treatment of all research participants will be in accordance with the Equal Status Act (2000). All researchers must adhere to both national and international legislation and codes of practice relevant to research endeavours.

INFORMED CONSENT

One of the major issues relating specifically to people with an intellectual disability is to ensure that the researcher has obtained informed consent before any research takes place. While many service users are capable of giving their consent to participate in research, a sizeable group will not have the capacity to consent to participation in research projects. A legal framework does not currently exist in Ireland for substitute, or assisted decision-making, other than the Ward of Court system.

Consent is an aspect of the right to autonomy. In other words, each person has a right to self-determination through the concept of consent. This right arises out of civil, criminal, human rights, and constitutional law (Keys, 2005). Three factors are necessary for true consent:

- Was consent voluntarily given, for example without threats, or inducements?
- Was the person properly informed before participation?
- Did the person have the capacity in law?

The Law Reform Commission has produced a *Consultative Paper on Vulnerable Adults and the Law: Capacity* (LRC DP 37-2005). This paper outlines the functional model of capacity which is the most widely accepted modern capacity model and thus merits particular attention.

The decision to consent should be based on a full appreciation of what the research is about and what is expected of potential participants. It should also be clear to the individual how the research may or may not affect their current lifestyle/health. Individuals may feel that they have no choice other than to participate, or the researcher may be in a position of authority over the individual concerned. In such circumstances and where

appropriate, it may be necessary to arrange for a third party to seek the consent of those involved.

In order to communicate this type of information to persons with intellectual disability it is essential that the researcher is familiar with various forms of augmentative communication aids (such as, a visual based systems).

ETHICS COMMITTEE

The role of the ethics committee is to provide the independent advice to participants, researchers, sponsors, employers, organisations and professionals on the extent to which proposals for research studies comply with recognised ethical standards. Researchers must familiarise themselves with the National Disability Authority document, *Ethics in Disability Research* (2002).

“The underlying principal of the Ethics Committee is that in relation to research on human subjects, considerations related to the well being of the human subject should take precedence over the interests of science and society. It is the duty of the Ethics Committee in research, to protect the life, health, privacy and dignity of the human subject. (World Medical Association, Declaration of Helsinki, 2000).”

Therefore the role of an ethics committee in accordance with the World Medical Association is as follows.

- Protect and safeguard the rights and interests of the participants;
- Balance the benefit of the likely advance in knowledge against the discomforts and risks of taking part in the research;
- Ensure and monitor appropriate confidentiality;
- Decide whether and how the participants of research will be able to give free informed consent and examine the process by which this consent was obtained – in particular in the case of consent by proxy;
- Determine and monitor when there is a breach of best practice and determine the penalties attached to such a breach for both the organisation and the individual researcher;
- Act as an independent source in relation to any questions service users and their families may have about research projects pertaining to them; and

- Determine whether the research is likely to be of benefit to the participants being researched.

It is recommended that a Research Ethics Committee be made up of a minimum of three relevantly trained members of the multi-disciplinary team within a Local Company plus an external member. It is critical that members of the Research Ethics Committee excuse themselves from the review of a study if a conflict of interest issue arises. Alternative Research Ethics Committee members must be sourced in such circumstances.

RESEARCHERS OBLIGATIONS AND ACCOUNTABILITY

It is essential that researchers conduct themselves in a professional manner characterised by openness, honesty and objectivity and adhere to relevant professional codes of conduct.

- They must respect and ensure that the dignity, rights, safety and well-being of all actual or potential research participants is upheld.
- They must receive free and informed consent from the appropriate source. In the case of children this should include the child as well as parents/guardians.
- They must ensure that considerations related to the well-being of the participant takes precedence over the interests of the research itself. Efforts should be made to anticipate and guard against any possible harmful consequences of research.
- They must keep personal notes, data and files pertaining to the project in a secure place to ensure compliance with both the Data Protection Acts and the Freedom of Information Act.
- They must be aware of the ethical issues surrounding research with people with Intellectual Disabilities including, communication, consent and implications of disability.

- They must act with openness, transparency and honesty and at every state of the research especially in respect of recognition of others work, reporting of data, and the rules of plagiarism.
- They should ensure that there is no fabrication, falsification, plagiarism or other unethical practices at any stage of the research and that the findings of the research are reported accurately and truthfully.
- They are responsible for the dissemination of results of project findings to participants/and or their families, other professionals, organisations in the public domain in an appropriate manner.

While incidents of scientific misconduct are relatively rare they raise serious concerns when they arise. Any complaints regarding scientific/research related misconduct must be reported to the Services Area's formal complaint system and reviewed by the Research Ethics Committee for assessment and appropriate action.

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Appendix 1

INFORMATION FOR RESEARCH APPLICANTS

The Brothers of Charity welcomes any research which will contribute to the welfare of its clients and which will result in an improved quality of life for them. We believe that research, which is carried out responsibly, objectively and honestly has an important contribution to make in the development of our services.

Our policy is to encourage any such research, while safeguarding the dignity, privacy and confidentiality of clients and their families. Our aim is to maximise the positive outcomes of research involvement for participants.

Before carrying out any research using Brothers of Charity clients as participants, or using Brothers of Charity Services' facilities, intending researchers must;

- Submit a written Research proposal (200 to 500 words) to the Research Ethics Committee;
- Submit a sample of all questionnaires, checklists or other data-gathering materials to be used in the research;
- Read, understand, and comply with the one-page document "Ethical Considerations to be taken in to Account when applying to the Brothers of Charity Services to conduct Research";
- Complete the "Questionnaire for Intending Researchers" and;
- Sign a Confidentiality Form.

The Brothers of Charity Organisation will retain joint ownership of research results and data with the Researcher. This means that the researcher can do what he/she wishes regarding dissemination and publication provided they abide by the greed ethical provision. The Brothers of Charity hold equal rights:

1. to disseminate such results for publication in print, in exhibition form or on-line,
2. to hold a copy of the research in its Library, and
3. to edit such results for inclusion in such Brothers of Charity Services documents as the Annual Report or relevant Policy documents.

Please ensure that your research proposal has included the following.

- Full description of study with title.
- Numbers of participants required and full description of same.
- Methodology.
- Intended duration of research with start and finish dates.
- Names of sponsoring and/or supervisory authority for this research.
- Details of any funding.
- Any further requirements from the organisation.
- Any personal information which it may be necessary for the organisation to know while you are conducting research such as any particular health needs.

Please allow up to four weeks for a response from the Organisation to your research application.

Appendix 2

QUESTIONNAIRE FOR INTENDING RESEARCHERS

Before you submit your Research Proposal to the Brothers of Charity Services, please answer the following questions carefully.

NAME:

ADDRESS:

1. Course of study being undertaken: Name Institutions

2. What level of Supervision are you receiving? Contact name and number of Supervisor / Academic Tutor.

3. What methodology will you use to access data?

4. What is the number of participants? _____

5. Who is your participant group?

6. How will this research benefit the participants?

7. How will you protect the participants' privacy and confidentiality?

8. How will you obtain informed consent from participants?

9. What information do you plan to give to research participants prior to starting the research?

10. How will data be stored, and for how long will it be retained?

11. How do you propose to disseminate your research information and to whom?

12. Have you considered the boundaries of your professional competence and ensured that your research is within your level of expertise?

SIGNED: _____

Appendix 3

INFORMATION FOR RESEARCH APPLICANTS

ETHICAL CONSIDERATIONS TO BE TAKEN INTO ACCOUNT WHEN APPLYING TO THE BROTHERS OF CHARITY SERVICES TO CONDUCT RESEARCH

Positive Outcomes for Participants

Research involves the systematic gathering of information about other people, and the analysis of such information. Research should, as much as possible, maximise the positive outcomes of involvement for research participants. Research participants, whether service users or staff, should in no way suffer any adverse consequences as a result of their involvement.

Accuracy and Truthfulness

Research must be carried out with total intellectual honesty. Objectivity and accuracy in reporting are essential to any research, which is to contribute to human welfare.

The Right to Dignity and Privacy

Research 'subjects' should be treated with respect. The right to privacy is paramount. Research should not interfere with an individual's physical, social or moral welfare. Personal dignity, feelings and rights should be considered and respected.

Research with Vulnerable Groups

Research which involves vulnerable groups, should be particularly sensitive to their situation and should not compound their vulnerability. Consent to involvement in the research should be voluntary and conscious where possible, and every effort should be made to explain clearly to participants what is involved. If this is not possible, written permission must be sought and obtained from parents, guardians, senior family members or relatives, or other relevant authorities, before a vulnerable person is included in a project.

Confidentiality

Where appropriate, confidentiality should be strictly observed and anonymity guaranteed through the use of fictitious names, or numbers, or change of gender. If there are risks to confidentiality, they should be clearly stated.

Information

Research participants should have complete and accurate information regarding the research, its aims, the contracting agent or body, the level of supervision, the uses of the research and the ownership of the research. Researchers have a duty to caution subjects about any issues which research may arise such as raising unrealistic expectations.

Right to Withdraw

Research subjects should have the opportunity to discontinue the research process at any stage and for any reason they wish.

Dissemination of Research Findings

Dissemination of research findings is an integral part of the research process and should be executed in a manner which is suitable to the needs of the research participants.

Appendix 4

Brothers of Charity Services: Ethics Committee Checklist

	YES	NO
1. Is the research necessary?	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the research likely to result in a positive outcome for the participants?	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there any way that research participants could suffer any adverse consequences as a result of the research involvement?	<input type="checkbox"/>	<input type="checkbox"/>
4. Have the issues of confidentiality and anonymity been satisfactorily addressed and resolved?	<input type="checkbox"/>	<input type="checkbox"/>
5. Will full and informed consent be received from research participants?	<input type="checkbox"/>	<input type="checkbox"/>
6. Will an accurate and truthful level of information be given to research participants prior to commencement?	<input type="checkbox"/>	<input type="checkbox"/>
7. Will Brothers of Charity Organisation need to appoint a 'gatekeeper' in order to ensure that no pressure is put on participants?	<input type="checkbox"/>	<input type="checkbox"/>
8. Will research participants be told that they may withdraw if they so wish?	<input type="checkbox"/>	<input type="checkbox"/>
9. Has the Ethics Committee seen and passed all questionnaires and so on to be used in the research?	<input type="checkbox"/>	<input type="checkbox"/>
10. Who will keep the raw data? _____		
11. How will research data be disseminated and to whom? _____ _____		
12. Is the level of supervision of this research sufficient?	<input type="checkbox"/>	<input type="checkbox"/>
13. Has the Brothers of Charity Organisation obtained any relevant personal details such as particular health needs from the researcher which may be necessary to know during the period of research?	<input type="checkbox"/>	<input type="checkbox"/>
THIS PROPOSAL HAS BEEN PASSED	<input type="checkbox"/>	<input type="checkbox"/>

THIS PROPOSAL HAS BEEN REJECTED FOR THE FOLLOWING REASONS

THIS PROPOSAL WILL BE PASSED IF THE FOLLOWING CONDITIONS ARE MET

SIGNED: _____

DATE: _____