

**CONDUCTING
SERVICE BASED RESEARCH
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I am going to base my presentation today around ethical dilemmas that I encounter as a member of an Ethics Committee that reviews research proposals on a regular basis. I hope it will give you an idea about the types of issues that an Ethics Committee deals with. It will hopefully enable those of you who have yet to present Research Proposals before an

Ethics Committee.....to prepare and anticipate these issues.

As Margaret has referred to the various guidelines and Edel is covering policy, I have decided to take a very practical approach to my presentation. Although all of these ethical dilemmas seem very obvious, they are sometimes overlooked.

Some ethical dilemmas are:

1. OVERUSE OF PARTICIPANTS

People who have intellectual disabilities are a vulnerable group. They may be

approached repeatedly to participate in various research projects. It does not seem ethical for the same individuals to be approached again and again. Researchers may not be aware that the same target group, that is, the same individuals, may have been used recently for other research. An Ethics Committee tries to safeguard against the overuse of participants. Many committees suggest a time interval before the same individuals can be approached to participate in a 2nd research project. The research ethics committee in my organisation safeguards

overuse participants by seeking a 4 month interval between the same individuals being approached for research.

2. AWARENESS OF DIAGNOSIS

Although it seems obvious that participants should not become aware of their diagnosis through research, there have been many times when Ethics committees have had to raise questions in relation to this issue with researchers.

As the title of the research project appears on the consent form, it may include terminology that indicates either a

particular level of intellectual functioning or the presence of a mental health difficulty. If an individual, or their family, are unaware of a diagnosis, they should be excluded as potential participants.

It is the researcher's responsibility to ensure that participants do not become aware of their diagnosis through research.

3. RECRUITMENT

Margaret has already referred to recruitment in her paper. I intend to elaborate on some of the ethical dilemmas I have encountered in relation to recruitment:

These are:

a) DUAL DIAGNOSIS

If research is being conducted in the area of mental health, researchers may overcome people being unaware of their diagnosis if they either recruit or check

with the clinical team in relation to participant awareness of diagnosis.

It is important to ensure everyone who needs to be informed of the research is informed e.g., director, clinicians.

b) APPROACHING PARTICIPANTS

There are times when research is conducted by staff who work very closely with potential participants. An Ethics committee tries to ensure that potential participants are approached in an ethical way so that subjects do not feel coerced

to participate. Some examples may

be:-

Social care workers conducting research in a group home where they work.

OR

A staff member conducting a project with their own group at work. These

dilemmas may be overcome by having

regard to **HOW AND WHO**

APPROACHES POTENTIAL

PARTICIPANTS

CONSENT

Ethical research practice requires participants to give

INFORMED AND VOLUNTARY CONSENT

Consent is an ongoing process and consent may need to be checked and reviewed throughout the research process.

People can only give informed voluntary consent on the basis of information they receive prior to requesting permission to consent. This information is usually given in a letter of information.

LETTER OF INFORMATION

The Letter of Information should be written in

USER FRIENDLY LANGUAGE.

The language used should relate to potential participants. As many people

with intellectual disabilities have poor literacy skills, the researcher needs to consider:-

- The language used
- Ensuring all aspects of what is involved are clarified
- Types of support a participant may choose e.g., choosing advocate themselves to be present
- Varied methods of communication
- How findings will be disseminated

The following examples are ones that have arisen in research that I have reviewed:-

- Failing to explain the nature of the research project
- Using technical language that is meaningless to potential participants
- Not explaining the types of measures being used (e.g., assessment may be stated but potential participants do not know what this involves)
- Not explaining why the research is being conducted
- Failing to explain it is part of one's own research e.g., Master's
- Using language that the individual does not use

- Using too complex written language.
- Layout of information is not accessible to individual. This makes it difficult for the person to understand fully the nature of the research.
- If there are 2 or 3 groups being researched, the researcher needs to clarify to which group each participant belongs. This should be clearly indicated on both the letter of information and consent form. If this is not done, it may be very distressing to participants as they may think they have an additional difficulty or

diagnosis, such as a mental health problem.

- If records are being reviewed, the participants need to be informed of what records are to be reviewed so that they can give their consent to access records.
- If other agencies, such as, schools are also part of the research process, it is important that the parent gives consent for the school or child's teacher to be contacted.

- Offering feedback to participants in such a way the participant thinks they are getting individual feedback.

CONSENT AND CONSENT FORM

Potential participants can only give informed, voluntary consent on the basis of information they have received.

As Margaret has already highlighted the essential components of the consent form, I do not intend to spend time repeating them.

Researchers may believe that once the consent form is signed, the participant has

agreed to fully participate in the research process. In many cases, no problems arise. However, ethical issues may arise when the person is being interviewed. If a participant becomes distressed as part of the research process, they will usually be excluded from the research. The researcher will need to follow whatever protocol they have put into their research design for distressed subjects.

It can be difficult to know when to seek consent from when the person's capacity to consent may be affected. This issue arises not just for those who have

intellectual disabilities but also for others, such as, people who have dementia or psychosis.

(CHILDREN)

The legal situation is clear in relation to children who are used for research. Parents consent for children under 18 years. Although researchers will get

consent from parents, children's assent is also usually sought where possible.

(ADULTS)

The situation in relation to consent is more problematic for adults. This arises because the capacity to consent to the particular research may or may not be affected.

Adult participants should be involved as much as possible in the research process.

Adult service users who are in a position to understand the research should be

encouraged to give or withhold consent for research.

The capacity to consent may be affected by the type of research being conducted, for example, more intrusive research and its implications may or may not be understood by someone who has previously consented for other research. The researcher needs to decide if parents are or are not informed of the research.

From a legal perspective, people over 18 years give their own consent.

For people who have significant disabilities, their parents or family member usually act

as an advocate and give consent. If an individual seems distressed or uncomfortable when participating in research, it is an indicator they are not consenting to research and this should be respected. It is up to the researcher to check how an individual may show discomfort with the process.

Ethical dilemmas arise regarding consent for individuals who are living in residential centres and have little or no family contact. Ethics committees expect researchers to clarify how they

will explore the issue of adult consent and determine how and who may be most appropriate to approach where this is not the participants themselves.

RECORDING

Ethical issues arise in relation to

AUDIO RECORDING/TAPING AND VIDEO RECORDING/TAPING

If the research involves audio or video recording, participants must give voluntary and informed consent.

AUDIO TAPING

In relation to audio taping, ethical dilemmas arise if potential participants would like to participate in the research but do not wish to be audio taped.

In my experience, many researchers overlook to build this into their research design.

- If audio taping is essential for the research, this should be clearly stated.
- If audio taping is not essential, the researcher should offer participants a

choice of participating in the research with or without being audio taped.

- If participants do not wish to be audio taped, the researcher should look at how this can be overcome, for example, a second may need to be present to transcribe the interview.

All of this should be reflected in the letter of information and consent form.

VIDEO TAPING

Ethical dilemmas arise in relation to video taping.

Where video taping occurs for research, it is usually done as part of a group.

- How does the researcher avoid inadvertently capturing someone on video who has not given their consent?
- If one member of the group declines to be videoed, does this exclude them from the research?
- If video taping is conducted in other settings, for example, mainstream school or playgroups, how does the researcher get informed consent from people who are not active participants in the research? What happens to

those who do not consent? Do they have to be removed from the setting or room to enable the research to be conducted?

All aspects of video taping need to be carefully thought out and built into the research design.

DATA PROTECTION ACT

Researchers need to get consent if they wish to change the use of information which they obtained for a another purpose. The Data Protection Act is clear that people must give consent for

the change of use of information. However, this consent would be to look to use the information for research purposes.

INFORMATION KEPT ON PERSONS FILE

Where information is to be kept on a person's file as a result of research, this needs to be stated. In instances where information is kept on the person's file, the researcher needs to examine how

and who gives feedback in relation to this information.

There is a useful booklet that has been issued by the Irish Council for Bioethics called

**Operational Procedures for Research
Ethics Committees : Guidance 2004**

I would like to finish by leaving you with a checklist of ethical areas to consider based on my presentation:

- Inform others**
- Overuse of Participants**
- Awareness of diagnosis**
- Recruitment**
- Letter of Information**

- **Consent**
- **Reason for research**
- **Protocol for distressed participants**
- **Audio recording**
- **Video recording**
- **Protocol for information kept on person's file**
- **Dissemination of results**