Quality Research with Older and Disabled People: Theoretical, Practical and Ethical Issues

Workshop 1: Ethical Issues: Penny Duquenoy and Noelle Blackman

Most of the literature on research methods contains a section on "ethics", with the degree of ethical consideration largely dependent upon the type of research being conducted. Investigations concerning aspects of health, or vulnerable groups (such as children), prioritise the principles of informed consent, and confidentiality. The ethical issues addressed are either raised by the "sensitivity" of the research topic, or the vulnerability of the research subjects, or the difficulties posed in these two cases of establishing credible research results. For example People with learning disabilities may have a variety of support needs regarding dependence; these will include transport, accessibility and communication. There are also ethical issues about payment for work undertaken and the effect of this on benefits. One of the overall difficulties of involving disabled people, who often live lonely and isolated lives, in this kind of work, is the meaning that this often intense experience takes on for them and the impact of the loss of this part of their lives when the work finishes. It is an ethical issue for the researchers to consider this and to consider how to lessen this impact.

This workshop will begin with asking whether our research fits into the categories above. Is research into the usability of devices for older and disabled people a sensitive topic? Are older and disabled people a vulnerable group? In other words, what is new or different (if anything) about our research as far as ethical considerations are concerned? What should we be taking into account when considering research in this area?

The aim of this workshop is to stimulate discussion, encourage reflection, and formulate key aspects that require ethical attention. Starting points for discussion will be:

- Positive discrimination – is it good or bad in itself?
- Research relationships – do we have different responsibilities or obligations?
- Low-income research subjects – is payment appropriate?

Workshop 2: Validity of Results: Mary Zajicek and Lorna Lines

The aim of the workshop is to explore how the results of research into systems for older adults can be made available to the designing community. The workshop approaches the validity of results question by asking how useful the outcomes of research are and how easy to apply for those building systems for older adults and disabled people. Mary Zajicek will describe methods she has used to make her research results more accessible and it is anticipated that other researchers and those developing systems for older adults will describe how they go about the transfer of research results to usable systems. The workshop will also explore the validity of treating experimental results derived from work with older adults in the same way that we treat the results of experiments with younger subjects.
Workshop 3: Practical Issues: Gill Whitney and Helen Graupp

Quality research into the needs of elderly and disabled people requires input from elderly and disabled people. Methods of input can vary from evaluating the final product with those groups to using emancipatory research techniques. Currently many funding bodies require that users or user bodies be consulted in any research project. But what does consultation mean and how should research be conducted? There are number of practical issues that need to be considered in order to conduct successful research, these include:

- Suitable methods of working with elderly and disabled people. This includes the issue of mixed methods when there are a variety of disabilities.
- Communication issues. This includes issues of language and terminology and the use of interpreters for sign language and symbol languages such as Makaton.
- Payment for volunteers.

Workshop 4: Research Methods: Ray Adams and Suzette Keith

The careful selection and development of research methods is essential if research is to be of suitable quality and relevance. So how can the researcher hope to make good decisions when considering methods?

Traditional research methods observe, form hypothesis, quantify and measure change. The researcher is in charge, the measures are objective. But does this objectivity risk excluding or misrepresenting the needs of older and disabled groups? If we want to actively involve older and disabled people what methods should we chose? What changes to these methods or new methods are needed to support the empowerment of this user group?

The purpose of this workshop will be to work on the selection or development of suitable methods, to identify the options and gaps, as well as exploring user-lead research methods such as action research and participatory design. Discussion will include a significant focus on the objectives and beneficiaries of research in this field.