

ETHICS IN DISABILITY RESEARCH

‘ Ethics are a matter of principled sensitivity to the rights of others ’

(Bulmer, 2002 cited in RESPECT, 2003:4)

Research has an important contribution to make towards achieving full human rights and social justice for people with disabilities (CSPD, 1996; UN, 1993).¹

As the field of disability research in Ireland expands, it is vital that quality in such research be ensured. The NDA believes that **quality research** and **ethical research** are synonymous, so that adhering to ethical good practice is a quality assurance issue.

The NDA understands ethics to be

“ a set of standards by which a particular group or community decides to regulate its behaviour – to distinguish what is legitimate or acceptable in pursuit of their aims from what is not”

(Flew, 1979:112).

In accordance with its statutory role in relation to disability research, the NDA offers these guidelines as a resource to assist the expansion of quality disability research in Ireland. The guidelines have been drawn up through consideration of best international practice alongside a wide process of consultation, in particular consultation with people with disabilities.

The NDA advocates that disability research in Ireland adhere to the **Core Values** and **Ethical Guidelines** set out in this document. The NDA recommends that those responsible for approving new research projects in this field utilise this document to inform their decision-making processes.

These guidelines are designed to be used by those involved in funding, conducting, or managing disability research, most especially that which involves people with disabilities as participants. They do not replace existing general ethical guidelines in social and policy research but supplement them by providing an outline of key issues from a disability perspective². In some research it may also be necessary to refer to more detailed guidelines relating to

¹ Both the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993), and the 1996 report of the Irish Commission on the Status of People with Disabilities, stressed the need for a sound and comprehensive knowledge base in this area to provide the necessary grounding for evidence-based change.

² For an example of an Irish set of general social research guidelines see http://www.ucd.ie/sai/SAI_ethics.htm.
For an EU level example see <http://www.respectproject.org/code/index.php>.

specific groups, such as the IASSID guidelines for research involving people with intellectual disabilities³

These guidelines may also be of interest to people with disabilities and their organisations. However, further related documentation is also planned for the wider disability community. The NDA acknowledges that applying ethical guidelines in each individual research project is a process, and an on-going matter of judgement and good research practice. In some cases, difficult decisions may need to be made, including decisions which involve the balancing of core values against each other. In addition, not all aspects of the guidelines will be relevant to every research project⁴. Consultation with Research Ethics committees and peer review procedures can be useful in clarifying and resolving these issues.

In order to strengthen existing resources in this area, the NDA is establishing an NDA Disability Research Ethics Committee to assist and advise those engaged in disability research when making those decisions. This Committee will begin its work in 2005.

Over the coming years, detailed case studies will be compiled by the NDA Research Ethics Committee, based on the practical experience of utilising these guidelines. This information will be used to revise the guidelines where necessary, and to develop a database of useful examples showing how researchers have addressed ethical issues in real world disability research. This information will be made generally available by the NDA in the form of a good practice guide.

Core Values

The following core values underpin these ethical guidelines:

- 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

³ <http://www.iassid.org/>

⁴ For example, sections on informed consent would not be relevant to documentary research using public documents.

- 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

Guidelines for Good Practice in Disability Research

Adhering to these general core values presents some specific challenges for disability research. These challenges are discussed under the following five main headings:

Well-being and avoidance of harm
Collaboration
Consent
Respect
Equality and diversity

Well-being and Avoidance of Harm

The General Research Principles:

- The well-being of those involved must be at the centre of the research process
- Every effort must be made to anticipate any possible harm which might result for participants or others from the research process, and methods must be developed to minimise these dangers
- Research must not be used to deny established rights or restrict legitimate entitlements
- All legal responsibilities must be fulfilled

Implementation in Disability Research:

Researchers need to locate their work within the framework of the movement towards equality and human rights for people with disabilities, both in Ireland and internationally. So researchers may need to consider the content and implications of current UN instruments and the national legislative framework relating to the rights of people with disabilities. To ensure this

competence, researchers may need to undertake specialised training, including equality/disability awareness training.

Ethical research practice also requires that researchers make every effort to ensure that participants are not harmed by the research process at any level, from the individual to the social. Careful strategies are needed in implementing this principle, especially when researching in care settings; or where advocates, interpreters or proxies need to be used in aspects of the research, most especially data collection. Relevant laws also need to be understood and complied with.

Clearly, researchers cannot fully control the use to which their research is put. Therefore, the ethical responsibility to ensure that harm does not result from research after it is published, is one which falls on others as well as the researcher(s). These others can include media, policy-makers, service providers and other stakeholders. However, the researcher also has a responsibility to challenge such misuse when it occurs, publicly if necessary.

Two further specific considerations exist, at the group and the social levels.

Firstly, researchers need to be aware that some people with disabilities feel “over-researched” (Mitchell, 2003). Careful thought needs to be given to whether each individual research project can be justified and, most importantly, can contribute in a positive way to improved human rights and social justice for people with disabilities. A collaborative approach will assist in this aspect of research design and planning.

Secondly, researchers must recognise the particular concern of people with disabilities and their organisations, that research might be linked with theories, ideologies, or policies which contradict core human rights principles (as has happened in the past). Such research is unethical and should not be undertaken.

Collaboration with People with Disabilities

The General Research Principle:

- Participation in research by the people directly affected, and their organisations, must be promoted

Implementation in Disability Research:

Researchers, along with research managers and funders, need to be sensitive to the history of exclusion of people with disabilities from research and of the abuse of people with disabilities by some forms of research.

The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) state that:

States should facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.

So, people with disabilities must be involved in a meaningful way in research on their lives and experiences. This involvement needs to be accomplished through genuine and well-planned processes of collaboration and consultation with people with disabilities. Such collaboration and consultation needs to be integrated into each research project at all stages, from planning to communication of the conclusions to participants and dissemination of the research findings.⁵ Furthermore, such exercises must be documented explicitly and then audited when the research has been completed. Bodies which have a say in approving or refusing new disability research projects, such as Ethics Committees, must include members with disabilities and/or representatives of disability organisations.

In 2002, the NDA developed a set of detailed and practical guidelines (referenced in footnote 5) which examine various strategies for collaboration and consultation between researchers, people with disabilities and their representative organisations.

⁵ For some examples of good practice see NDA (2003) *Using Emancipatory Methodologies in Disability Research: proceedings of the first NDA conference on Disability Research*. Dublin: NDA (www.nda.ie).

These NDA guidelines argue that some key considerations should be applied to any inclusive disability research. These are:

- Planning for inclusion
- Making the research process accessible
- Using appropriate language
- Being 'disability aware'
- Being sensitive to the use of language
- Making research reports accessible and available

The diverse nature of research means that the various ways of including people with disabilities will need to be considered in order to decide which one is appropriate for a particular study. Some projects may also involve different ways of including people with disabilities at different stages of the research process.

Some models of inclusion which researchers, managers and funders can consider are:

- Participatory approaches to research
- Steering and advisory committees
- Consultation and planning groups
- Employing researchers with disabilities
- Having people with disabilities as research consultants
- Having people with disabilities as research respondents

These models are discussed in detail in the NDA guidelines.

Research managers and funders, as well as researchers, must recognise that participation and consultation strategies have implications for timeframes and budgets if they are to be implemented effectively.⁶

⁶ See guidelines on research governance from UK DOH for a comprehensive discussion of the various roles and responsibilities of managers, researchers, sponsors etc
<http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopmentAZ/ResearchGovernance/fs/en>

Consent: Informed and Voluntary

The General Research Principles

Voluntary and informed consent must be obtained from all participants

Exceptions to this principle, such as covert research, must be convincingly justified⁷

Implementation in Disability Research:

Ethical research practice requires that participants are included only on the basis of informed and voluntary consent. Often this means more than a single act of giving consent. It may mean an on-going negotiated process through the various stages of the research project. This process includes provision of comprehensive, accessible information on the research before requesting participation; discussions with potential participants and/or parents and advocates; the signing of consent forms or letters; reviewing consent issues as they arise during the research.

The issue of consent is arising more frequently within the current disability research context, where, unlike in the past, the thrust is towards research which uses proxies⁸ as seldom as possible. If the goal is to include people with disabilities (both adults and children) so that they speak for themselves rather than be spoken for by others, then particular attention may need to be paid to providing such **facilitating resources** as:

- Appropriate, accessible and detailed information
- Varied and appropriate methods of communication
- Employment of advocates and interpreters where needed
- Continued consent negotiation throughout the research process.

These will have implications for both timeframes and financial resources and must be incorporated into the research design from the start.

At the core of the consent issue is the concept of capacity: the decision as to whether a person has or has not, or has to a diminished extent, the ability to understand both that

⁷ An example of covert research which might be justifiable would be research on perpetrators of child abuse, where covert methods might be the only way that such harmful and criminal activity can be researched.

⁸ Proxies are people who speak on behalf of others or about others such as parents speaking about their children.

to which they are being asked to agree and the implications of such agreement. The matter of determining capacity may be especially complex in some disability research. This is likely to be the case, for example, where the focus is on disabled children, on people with intellectual disabilities, people experiencing mental distress or people utilising some forms of medication, which could give rise to doubts about their capacity. There is then a further, and related question, as to who can and/or should make a determination in the matter of capacity.

Therefore, researchers need to:

- develop their expertise and knowledge in this area, including legal knowledge;
- review relevant examples of good practice;
- consult with other experts as appropriate;
- recognise that these experts include peers and family members of the people with disabilities;
- be open to diverse forms of negotiation and communication
- use the ethical approval process to gain informed input into this process.

All these stages in designing and implementing the consent procedures must be documented and reviewed.

A further complexity arises when the research focus is on people living in residential institutions, or other situations in which potential respondents/participants may feel pressurised to give consent. In such cases, there is a greater onus on the researcher to ensure that no undue pressure is placed on individuals in order to ensure their participation and that there are no negative consequences for those who refuse. Only then can the consent be genuinely voluntary.

To summarise, researchers in the field of disability need to pay particular attention to:

- Minimising the use of proxies, while maintaining good practice in relation to consent
- Methods and legal issues in determining capacity to consent
- Facilitating and empowering potential respondents to consider their decision in a full, free and informed manner
- Documenting the consent process in all its stages
- Continued review of the consent process at all stages of the research.

Respect for Participants: Dignity, Anonymity, Privacy, Confidentiality and Legality

The General Research Principles:

- The dignity of participants must be respected throughout the research process
- Anonymity, privacy and confidentiality must be ensured at all stages, including the final stage of data storage/disposal

Implementation in Disability Research:

Ethical research practice requires that participants be treated with respect at all times during the research process and that anonymity, privacy and confidentiality be ensured. Disability research is no different from other research in this regard and standard ethical guidelines for social research cover such issues adequately for most disability research. In addition, to ensure that this principle is fully honoured, all researchers in this field must be trained in disability awareness and the research methods being considered at the design stage need to be comprehensively disability-proofed.

Furthermore, specific strategies for ensuring anonymity, privacy and confidentiality may need to be implemented when researching people with disabilities

- in care settings;
- where advocates, interpreters or proxies need to be used,
- in other situations where other people, besides the researcher(s) and the participants, need to be involved in aspects of the research, most especially data collection.

It is the responsibility of researchers to ensure that the research design is implemented in such a way that the specific ethical challenges in these settings are met. This may imply that special training will need to be undertaken by all those involved in the research team, including interviewers and those inputting and storing data, as well as the main researchers⁹.

⁹ For detailed recommendations on training interviewers see Browne et al 2003.

Strategies for ensuring that the consent obtained is both informed and voluntary are the subject of a separate section of these guidelines. They are at the core of ethical research based on respect for participants.

Researchers also need to fully comprehend and comply with relevant legislation, including laws relating to data protection, freedom of information, child protection and protection of vulnerable adults.

Equality and Diversity

The General Research Principle:

- Equality and diversity among people must be included as research design and planning issues

Implementation in Disability Research:

Ethical disability research is located within an understanding of the inequality and exclusion currently experienced by many people with disabilities. It focuses on the disadvantages imposed by disabling societies on people with physical, sensory, intellectual impairments or experiencing mental distress.

However, it is important that researchers understand that differences between people with disabilities co exist with the shared experiences of disablement. Thus, researchers must also incorporate into their research strategy recognition of the complexity and diversity that exists within the disability community. They need to recognise that the lived experience of disablement is shaped by the impact of other social characteristics / factors (Zappone, 2003).

Thus the Irish Employment Equality Act, 1998 and the Equal Status Act, 2000 outlaw discrimination on nine distinct grounds, which are:

- gender;
- marital status;
- family status;
- age;
- disability;
- race;

- sexual orientation;
- religious belief;
- membership of the Traveller Community

When researching people with disabilities, researchers may need to consider diversity along the other eight grounds, and to recognise that the experiences of disability, and of disabling processes, may vary depending on disabled people's membership of these other social categories, either singly or in combination. The impact of other aspects of diversity may also need to be considered, such as geographic location or socio-economic background.

Diversity within the disabled community has implications for research design and methodologies and these must be tackled. Some examples of these implications are:

- The need to consider varied communication strategies for diverse cultural groups within the disability sector;
- Finding appropriate access and consent strategies, especially when researching very vulnerable populations such as disabled asylum seekers or young gay and lesbian people with disabilities;
- Using sampling strategies which ensure that the samples reflect the diversity of this group;
- Ensuring that researchers involved in the research project are appropriately trained in equality and diversity matters.

Some Further Reading

Commission on the Status of People with Disabilities (1996) *A Strategy for Equality*. Dublin: CSPD

Browne et al (2003) *Designing and Piloting an Irish Disability Research Instrument based on WHO ICF*. <http://www.nda.ie/>

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