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AGREEMENT OR ACQUIESCENCE?

issues of informed consent within research working with vulnerable adults & the Mental Capacity Act (2005) (learning disabilities)

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A SOCIAL WORK RESEARCH PROBLEM: METHODOLOGICAL CHALLENGES

PEOPLE WITH LEARNING DISABILITIES: ISSUES OF VULNERABILITY

People with learning disabilities feature as a small percentage of the total population (i.e. 1.5 million), DoH (2001c) but figure highly in terms of need for support in leading ordinary lives. Many people with learning disabilities are among the most socially excluded and vulnerable in the UK and there is increasing evidence that many still experience abuse, bullying and frequent challenges to their citizenship and rights.

TERMINOLOGY: A PARADIGM SHIFT

The term 'learning disability' has been used since the early 1990s to refer to 'this 'client' group. The term sanctioned by the Department of Health (Fenge et al., 2010). However, the term is not universally supported by many people. Some prefer to use the term 'learning difficulty' (Healthcare Commission, 2007b).

The last twenty years has been characterised by an emergent new paradigm for understanding disability and learning disabilities. In this view, learning disability is not a condition of the individual, but places an emphasis on some barriers to inclusion.

According to (Swain et al., 2004) these barriers to inclusion may include the following:

- Social restrictions in the world around them
- Attitudinal barriers as opposed to the experience of having a disabling condition
- The reinforcement of disability through encounters with disabling barriers
- The experience of disability may often be an experience of oppression
- Organisations and institutions, education, health and social care agencies may represent paternalistic and unresponsive services
- The lack of positive role models through language and culture
- Invisibility of the disability agenda in the media



A RESEARCH PROBLEM: ISSUES OF INFORMED CONSENT

Obtaining consent to participate in research presents particular ethical challenges to researchers in the field of learning disability (Cameron and Murphy, 2006). A significant tension exists between ensuring that people with a learning disability understand the nature and implications of their involvement in research, and at the same time to avoid any sense of coercion.

I believe we must recognise that, although some people cannot give informed consent, efforts must still be made to develop ethical practice so that they are not entirely excluded from research. Therefore, it is necessary to adhere to both academic requirements and legal implications that arise from the Mental Capacity Act (2005) in relation to working with those who lack capacity to make certain decisions.

WHAT DOES THE LITERATURE SAY?

The Research Relationship

A primary feature of qualitative research is the importance of the quality of the relationship between researcher and participant. Walmsley (2004) argues that:

- The terms of engagement need to be established and boundaries maintained
- Research with vulnerable groups makes examination of this dimension paramount
- Rapport building requires particular skill and needs to be monitored (Cameron and Murphy, 2006)

Stalker (1998) asserts, that we need to be particularly sensitive to this relationship. Researchers going into people's homes as self-invited guests could be perceived as being intrusive but are actually more likely to be misconstrued as being their friends. Researchers can add to 'the succession of different faces drifting in and out of people's lives' over which they have no control (Stalker 1998, p.10).

THE LEGISLATION: The Mental Capacity Act (2005)

Getting informed consent to participate in research has become a legal requirement as well as a moral obligation. Scott et al., (2006) outline the three key issues:

- The person's competence to give consent
- The extent to which the research is in the person's own best interest
- The balance with public interest

With regard to competence to give consent, historically people with learning disabilities have been considered unable to make decisions for themselves. Attitudes to this have changed, as reflected in the legal requirements in the Mental Capacity Act.

Drivers for reform have included:

- the legal context
- demography, an acknowledgment that England and Wales have an ageing population
- improvements in healthcare
- developments in policy, particularly in community care
- protection of human rights (Lyne, 2010)

The Five Principles of the Act

1. Protect people who lack capacity to make their own decisions and ensure that individuals are encouraged to participate in the decision-making process, whatever their state of mind or health.
2. Help individuals make their own decisions, using different techniques when working with someone with a learning disability.
3. Acknowledge the individual's right to make an unwise decision without having their capacity brought into question.
4. Act in the person's best interest (the most fundamental principle in the Act).
5. Consider whether there is any need to intervene at all.

TOWARDS A RESOLUTION PhD RESEARCH STUDY

Research Focus: To ascertain the value and role of social work within a multi-disciplinary learning disability team in the northwest region in England.

One of the aims: to include service users

- To gain their perspectives about the benefits (as perceived by them) or otherwise, of working with a multi-disciplinary learning disability team
- To discuss the effects this has upon their lives
- To include a number of adults in the qualitative research project
- The participants will have a range of learning and communication disabilities.

Research Supervisor: Professor Steven M Shadlow

METHODOLOGIES WHICH CAN ADDRESS: ISSUES OF INFORMED CONSENT & THE REQUIREMENTS OF THE MENTAL CAPACITY ACT

MY APPROACH

My research study is of an exploratory nature. It is particularly well placed within the interpretive paradigm underpinned by a hermeneutical, phenomenological approach (Heidegger, 1962).

Entering into a research relationship can potentially extend a person's social network, and as a researcher, I need to consider what this means and feels like from the perspective of research participants with learning disabilities.

Research Methodologies: International Perspectives

It is my intention to use a variety of methodologies drawing upon international perspectives. Most of the research with people with learning disabilities addresses the problem of informed consent by highlighting:

- The problem of informed consent
- The quality of the information: who it goes to and how
- The process of supporting participants to express views and not just acquiesce

'A BAG OF TOOLS'

This methodology is based upon a study undertaken in New Zealand (Munford et al., 2008) to help with research relationships. This bag, unpacked as part of the scene-setting routine in the field, includes physical objects or props that act as reminders that 'as we build rapport and develop relationships we are there as researchers' (p337).



TALKING MATS™

The use of Talking Mats spans the globe from countries as diverse as India, USA, Australia, Germany, Finland, Malaysia, Sweden, Brazil, South Africa, Canada and Spain.

Talking Mats™ is an inexpensive, low-tech visual communication resource that helps people with communication difficulties to express their thoughts (Cameron and Murphy, 2006). It uses three sets of symbols – topics, options and visual scale – and a mat on which to display them. The topics relate to whatever the person wants to talk about.

For people with a learning disability choices can often be limited and it can be difficult to ensure their voice is heard. This is particularly true for those people with a learning disability who also have communication impairment.



PROXY CONSENT

The need for consent is distinct from the need for assent (Scott et al., 2006) and as a researcher this will involve people who know the person establishing both. Kellet and Nind, (2001), in addressing research on (not with) people with profound impairments, used a network of people around the participants – people who understood them, 'cared about them, knew when they were unhappy, distressed or uncomfortable' (p53). It is often family members and advocates who can best advise on the individualised, sometimes idiosyncratic communication necessary to the interaction.

WHO SHOULD CONSENT TO RESEARCH? A RELATED STUDY FROM QUEBEC

This study looked at opinions regarding who should consent to research on behalf of an older adult suffering from dementia. Bravo et al., (2003) found that where the research does not involve high risk to the participant, most respondents preferred that a close relative or friend also be involved in the decision, despite not being legally appointed.

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