Agreement or acquiescence? Issues of informed consent within research working with vulnerable adults & the Mental Capacity Act (2005) (learning disabilities)

Lawrence, J

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

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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)

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 views in the qualitative research project
- The participants will have a range of learning and communication disabilities.

Research Supervisor: Professor Steven M Stanbroe

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’ (p.337).

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 scales – 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. Relief 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, ‘spoke 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.

Bibliography


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