Specialist Research Ethics Guidance Paper

DOING RESEARCH WITH PEOPLE WITH LEARNING DISABILITIES

This paper discusses some of the ethical implications of undertaking social research (including social care research) with adults with learning disabilities and should be read in conjunction with wider ethics policy documents which can be found on the University of Sheffield’s Ethics Policy website. Documents that are of particular relevance include:

Research Ethics Policy Note no. 5, 'Ethics review of health and social care research'
www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy/policy-notes/health-social-care

Research Ethics Policy Note no. 2, 'Principles of consent'
www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy/policy-notes/consent

Report of Ethics Workshop on Research Involving Adults who Lack the Capacity to Consent (24 May 2011)
www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy/further-guidance/educationresources/mencapworkshop

Specialist Research Ethics Guidance Paper entitled 'Research involving adult participants who lack the capacity to consent'

This paper takes a broad view of research ethics and includes discussion of the historical relationship between the academy and the category of ‘learning disability’ and the power dynamics of contemporary relationships between people with and without learning disabilities. It makes no claim to cover all, or even most, of the ethical issues that can arise when undertaking research with people with learning disabilities but includes discussion of the following areas:

- The academy and learning disability
- Understandings, definitions and terminologies
- Capacity to consent to participate in research
- Power and control in the lives of people with learning disabilities
- Paying research participants and co-researchers
- Literature reviews
- Accessible research summaries
- Pseudonyms or real names?

The academy and learning disability

During the first half of the twentieth century, academic research played a key role in creating the ‘learning disability’ category as ‘certain kinds of individuals emerged hand in hand with new techniques of gathering knowledge about them’ (Carlson 2010, p. 46, emphasis in original). Research also provided academic legitimation for the institutionalisation of these individuals (Ryan and Thomas 1987).

“The diagnosis ‘mentally deficient’, especially when supported by the whole armoury of statistical diagnostic procedures, became convincing evidence for the necessity of removal of the ‘afflicted’ from free society. [...] Science (including medical and social sciences) in general and the university in particular provided legitimation for this sequence of events” (Radford 1994, pp. 15-16).
Within higher education and research institutions, people with learning disabilities were studied by academic researchers, some being subjected to abusive research practices. For example, between 1945 and 1953, ‘ineducable’ children at the Vipeholm Institution in Sweden were given copious quantities of sweets and sugary foods in order to study the effects of sugar on the decay of their teeth (Gustafsson et al 1954; Krasse 2001), while ‘retarded’ children at Willowbrook School in the US were deliberately infected with hepatitis during the 1950s and 1960s, in order to study the progression of the disease (Krugman et al. 1962). On the other hand, academic research has also had positive impact on the lives of people with learning disabilities, playing a key part in exposing abusive practices within the institutions (for example, Oswin 1978) and discrediting the ‘science’ of eugenics (Radford 1994).

Because the lives and experiences of people with learning disabilities were understood as antithetical to academic life, there was little space for their voices or perspectives within academic research. As Chris Kiernan (1999) has observed, it was not until the 1980s that people with learning disabilities were involved even as interviewees in research that was about them, or their views sought in evaluations of the services they received. In the UK, from the 1980s onwards, people with learning disabilities were discharged from the long-stay hospitals and ‘resettled’ in their ‘communities of origin’. By then, children with learning disabilities were no longer being routinely institutionalised and many remained ‘in the community’ as adults. Policy imperatives promoting ‘service user involvement’ led to a range of service users, including people with mild and moderate learning disabilities, being involved in health and social care service planning and also in research (Boxall et al. 2004; 2007). Most people with learning disabilities now live in community settings but are among the most disadvantaged in our society (Emerson et al. 2005; 2008). For many, violation of their human rights is ‘a normal part of their every day lives’ (JCHR 2008, p. 16; ECHR 2011). As indicated above, there is clear historical evidence of the abuse of people with learning disabilities within research (Gustafsson et al. 1954; Krugman et al. 1962) and the potential for such violation within contemporary learning disability research remains. The involvement of people with learning disabilities as participants and co-researchers and the use of visual approaches – which may be more accessible to people with learning disabilities than text-based methods – have raised further ethical issues, some of which are explored in this paper.

**Understandings, definitions and terminologies**

Discussions about learning disability often refer to ‘lack of intelligence’, chromosome ‘disorders’ and other ‘clinical abnormalities’. These ideas are consistent with individualistic understandings of learning disability (Oliver 1990), which locate ‘problems’ within identified individuals with learning disabilities and frequently attribute biomedical causes to the difficulties they experience. Official definitions of learning disability also tend to adopt ‘individual model’ approaches; for example, the *Valuing People* White Paper, which sets out the government’s strategy for learning disability for the 21st Century, offers the following definition:

Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.


This definition is further qualified by a note that ‘“learning disability” does not include all those who have a “learning difficulty” which is more broadly defined in education legislation’ (Department of Health 2001, p. 15). The term ‘learning difficulties’ however is the preferred
term of many self-advocacy groups (see for example, Emerson et al. 2005, Learning Difficulties Research Team et al. 2006). In these contexts, ‘learning difficulties’ is used synonymously with ‘learning disabilities’, but only in the sense that the same people might be included by the use of either term. Despite the stated preferences of many people with learning difficulties, the ‘field’ of learning disability is defined and controlled by those responsible for research, policy and practice in this area, who have promoted the term ‘learning disability’ in the UK. More recently, the research community has advocated moving towards terminology with international recognition, and the term ‘intellectual disability’ has been proposed (Schalock et al. 2007). Within the UK, the Department of Health report Raising our sights: services for adults with profound intellectual and multiple disabilities (Mansell 2010) has adopted ‘intellectual disability’ terminology. However, there does not as yet appear to be a general trend towards use of the term ‘intellectual disability’ within UK policy and service discourses, though the term is increasingly being used in academic publications. The international research community’s naming of people’s experience in this way also raises ethical issues. However, shared terminology and understandings are essential for international collaboration and the International Association for the Scientific Study of Intellectual Disability has endorsed guidelines on international multicentre research involving people with intellectual disabilities (Dalton and McVilly, 2004).

Learning disability is a contested category (Rapley 2004, Carlson 2010) and decisions about which participants to include (or not include) in learning disability research may be far from straightforward. Charlotte Davies argued (1998) that inclusion within the ‘learning disability’ category is inextricably linked to receipt of learning disability services. This ‘pragmatic’ definition of people as having learning disabilities or learning difficulties by virtue of their receipt of learning disability services is, however, changing, as inclusive education policies and social care services blur the boundaries of the learning disability category. As Jan Walmsley and John Welshman (2006, p. 6) observe, it is now possible for people to be in receipt of a range of services and benefits which are not learning disability-specific and ‘unless defined by their past as more traditional service users, they cease to be readily identifiable as people with learning difficulties.’ People with learning disabilities have, however, argued that even in situations where they are not visibly associated with learning disability services they are still perceived as ‘different’ by members of the public (Docherty et al. 2010).

Finding people with learning disabilities independently of the service system can, therefore, prove difficult as people may not have sufficient literacy skills to access the internet or read advertisements, though local advocacy groups may provide a good starting point. Recruiting adults with learning disabilities as participants in a research project may also be hampered by a range of gatekeepers; parents/carers, social workers, health professionals and others, who may feel that participation in research is not a good idea for the people with learning disabilities in question; rather than leaving the individual concerned to make up her/his own mind about whether or not to participate, they may discourage their participation, or fail to pass on information about the project.

The definitions of learning disability used by researchers clearly also have ethical implications, as do the various terminologies employed. Conventions surrounding terminology are not static and it is important to acknowledge the impact of changing terminologies in the area of learning disability, including historical terms which now have derogatory connotations for example, ‘idiot’, ‘imbecile’ and ‘moron’. People with learning disabilities have objected to the use in research of terminology that they perceive as derogatory, including the term ‘mental handicap’ (Docherty et al. 2010). For researchers who adopt a ‘social model’ of disability (Oliver 1990), understandings of learning disability are
about locating ‘disability’ within social, economic and political barriers to inclusion in the mainstream of society, rather than in individual deficit. These barriers – and their removal – are the focus, and raison d’être, of ‘social model’ or ‘emancipatory’ disability research (Barnes 2003, Barnes and Mercer 2010). Decisions about how disability is understood - for example, as located in individual deficit or in external barriers - also therefore have ethical implications. ‘Social model’ researchers often signal their commitment to social model understandings of disability by using the term ‘people with learning difficulties’, rather than ‘people with learning disabilities’. In ‘social model’ discourse, the word ‘disability’ is used to signal socially created barriers to inclusion, rather than fixed and inherent properties of disabled individuals; it would not be logical, therefore, to talk about ‘people with socially created barriers’. In ‘social model’ literature, the word ‘impairment’ is commonly used to refer to disabled people’s functional limitations and differences and the term ‘disabled people’ is used to indicate that people with impairments are disabled by economic, social and political barriers.

Although ‘social model’ ideas have undoubtedly influenced UK disability policy and practice, they are not without their critics, some commentators arguing for understandings of disability, including learning disability, located in a recognition of individual deficit rather than in social structures, while others again adopt a compromise position between the two poles. Arguments of this nature continue to be rehearsed vociferously within UK disability studies (see, for example, Shakespeare 2006; Sheldon et al. 2007).

**Capacity to consent to participate in research**

Good practice regarding consent to participate in research applies to people with learning disabilities in the same way as it applies to any other ‘human subjects’ (see Wiles et al. 2008). Many people with learning disabilities are capable of understanding verbal or written information about research and deciding for themselves whether or not they wish to participate. Others may struggle to understand some of the vocabulary used by researchers in spoken explanations or may be unable to read or write. In these situations, it may be helpful to produce ‘accessible’ consent and information sheets or DVDs explaining the research, which people can take away and review before deciding whether to participate. A number of organisations now produce pictures on CD that can be used to make documents more accessible:

See, for example, the Picture Banks produced by CHANGE - [www.changepeople.co.uk](http://www.changepeople.co.uk). These can be inserted into large print Word documents to produce ‘easy read’ versions. A guide to making easy read documents is also available as a free download from the CHANGE website [www.changepeople.co.uk/productDetails.php?id=2010](http://www.changepeople.co.uk/productDetails.php?id=2010).

However, for some people with severe learning disabilities or those identified as having ‘profound and multiple learning disabilities’, communication may be idiosyncratic (Mansell 2010) and researchers may be unable to communicate directly with these individuals; the use of ‘interpreters’ or ‘proxy respondents’ in these situations can raise further ethical issues (Stancliffe 1999; Clements et al 1999).
Some people with learning disabilities may ‘lack capacity’ to consent to participate in research (www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy/further-guidance/guidance), but it is important not just to assume this: decisions about capacity to consent are situation specific, and while an individual may not understand or have the capacity to consent to participation in Project A, they may understand and choose to consent to participate in Project B. Mental Capacity Act guidance concerning adults who lack capacity to consent to research has been published by the Department of Health (Department of Health 2008). This discusses the role of the ‘consultee’ whose responsibility is ‘to advise the researcher about the person who lacks capacity’s wishes and feelings in relation to the project’ (Department of Health 2008, p. 3). Although formalised procedures for ascertaining the consent of people with intellectual disability who lack capacity are new within the UK, proxy or surrogate consent procedures have been in place for several years in North America and Australia (Griffin and Balandin, 2004; Iacono and Murray, 2003, Iacono 2006). These procedures appear to offer a helpful approach to consent where individuals lack capacity, but in practice they have proved complex and concern has been raised that ‘researchers may come to rely extensively on surrogates to satisfy the increasingly stringent requirements of RECs [Research Ethics Committees] and IRBs [Institutional Review Boards]’ (McVilly and Dalton, 2006, p. 187).

Ethical approval procedures are designed to protect vulnerable research participants from harm. But in the UK, ethical approval processes required for people deemed to lack capacity to consent to research may be discouraging researchers from working in this area. Mental Capacity Act guidance (Department of Health 2009, p8) acknowledges that this could be ‘an unintended and unwelcome consequence of the MCA’. The same guidance also suggests that responses submitted on behalf of people ‘without capacity’ should be ‘excluded’ from any general surveys that do not have Mental Capacity Act approval (Department of Health 2009). The perspectives of people with learning disabilities who lack capacity (and indeed others with cognitive impairments) may therefore be ‘missing’ from research; this itself is an ethical issue (Boxall and Ralph 2009).

**Power and control in the lives of people with learning disabilities**

In almost all social situations, people with learning disabilities are less powerful than people without learning disabilities. Occasionally, people with learning disabilities may display ‘challenging behaviours’ in an attempt to assert power and gain control over a situation, but the balance of power may ultimately be restored to service providers through the use of restraint techniques or medication (Emerson and Einfield 2011). Even articulate people with mild or moderate learning disabilities who have been active in self-advocacy groups and disabled people’s organisations may be all too aware that power lies ultimately with supporters without learning disabilities who interpret inaccessible written materials or facilitate management of the organisation’s finances (Goodley 2000). People with learning disabilities who participate in research are likely, at least initially, to view university researchers in the same way as they view others who wield power in their lives and they may therefore want to ‘do the right thing’ or to do what they feel will ‘please’ university researchers. They may also have had previous bad experiences of education establishments and of ‘failing’ educationally, or previous experiences of abuse, particularly if they have lived in institutional settings (there is clear evidence of contemporary as well as historical institutional abuse – see for example Care Quality Commission 2011); because of these experiences, people with learning disabilities who participate in research may be reluctant to express views or opinions as they may fear repercussions. All of these factors can contribute to an unusual research dynamic between university researchers and people with learning disabilities; it is important therefore that university researchers earn the trust of people with
learning disabilities and develop research relationships that do not abuse their positions of relative power.

Power issues are also clearly of direct relevance in relation to consent to participate in research. One issue to be aware of, particularly where recruitment to the research project takes place in a service setting (for example a day centre) is that people with learning disabilities may be confused about whether or not researchers are service providers. If they consent to participate but later wish to withdraw from the research project they may fear ‘penalties’ for withdrawing, or loss of the services they currently receive.

**Paying research participants and co-researchers**

One of the ways in which participants’ or co-researchers’ contributions to research can be acknowledged is by paying people for their time. However, many people with learning disabilities are in receipt of disability benefits and financial reward may adversely affect their ongoing receipt of those benefits. This is a complex area. Many different organisations have tried to establish guidelines on payments but paying benefit recipients remains fraught with difficulties both because of financial reward and regularity of involvement (see for example, Turner and Beresford 2005, Commission for Social Care Inspection 2007). Even the way in which expenses are paid can cause problems for some benefit recipients (as they may be misunderstood as financial reward and benefits stopped pending investigation); where possible, reimbursement for travel expenses etc. should be made in cash. Although, in principle, it is good practice to build payment for research participants and co-researchers into funding proposals; in practice, some people with learning disabilities will be unable to accept payments without their benefits being adversely affected, whilst others whose circumstances are different may have no difficulties accepting payment. This can set up a situation where several people with learning disabilities involved in the same project are receiving differential rewards for their involvement. An alternative way of rewarding people is to build in generous budgets for refreshments, conference venues and (where necessary) overnight stays, so that people’s involvement can be valued in this way.

Some people with learning disabilities need support with personal care and may employ their own carer or personal assistant. Since the ‘personalisation’ of social care (as a result of which individuals are now given a personal budget with which to purchase their own personal care at an hourly rate: see Carr 2010), it is unlikely that an individual would receive funding from the local authority for personal care whilst participating in research. If the research project in question does not reimburse the cost of employing their personal assistant, the individual would therefore be out of pocket as a result of participating in the research. It is important therefore to build personal assistance costs into funding proposals; though carers should be paid direct as there are complications with making these payments to service users. People with learning disabilities may also need support to participate in research (assistance with reading/writing etc.) and it is a good idea to build funding for such support into funding proposals and also funding for taxis for those people with learning disabilities who are unable to access public transport.

Some research funders (for example Joseph Rowntree Foundation) require service users’ involvement in proposals for research funding. This can cause problems for university researchers as funding (travel expenses, personal care and support costs etc.) may not be available to include people with learning disabilities in the proposal writing process. Involving people with learning disabilities at the proposal writing stage, prior to ethical approval for the project, also poses an ethical conundrum.
Literature reviews
As mentioned previously, historically research has played a key role in the oppression of people with learning disabilities by legitimating their institutionalisation. Their (lack of) intelligence, ‘characteristic appearance’, behaviour and genetic make-up were identified, analysed, categorised and classified as ‘defective’ and on the basis of these supposed defects they were excluded from mainstream society (Ryan and Thomas 1987; Carlson 2010). Uncritical inclusion of oppressive research in a literature review may serve to perpetuate oppressive ideas about people who have learning disabilities: reviewing the literature is not therefore a value free or neutral activity as decisions about which literature to include and how it is to be reviewed also have ethical implications. In recent years there have been moves towards participatory research with rather than on service users, and service users have been involved across the research process, including literature reviews. The Social Care Institute for Excellence has published examples of service user participation in systematic reviews (see Carr and Coren 2007) but there has been little discussion of including people with learning disabilities in the processes of undertaking a literature review.

Accessible research summaries
It is good practice to offer to share findings with people who have participated in research projects. However, people with learning disabilities may find text-based information difficult to follow or understand and ‘accessible’ versions of research findings using large print and pictures may be helpful – see the ‘easy to read’ summaries at the Norah Fry Research Centre: www.bristol.ac.uk/norahfry/resources/online. Audio files or YouTube presentations can also be used to help make findings accessible. Although intended for people with learning disabilities, these accessible summaries may be popular with parents and carers and university researchers who are pressed for time!

Pseudonyms or real names?
The use of pseudonyms in an attempt to offer research participants anonymity is often regarded as ‘good practice’ in research involving people with learning disabilities, particularly where the research is in a sensitive area. However, research participants and co-researchers with learning disabilities - just like many research participants without learning disabilities - may not wish to be anonymous, preferring instead to take credit for the work they have done. Including people’s names in research reports, particularly where those reports (or accessible summaries) are published on the Internet may however have unintended consequences. For example, staff who have worked with an individual may read a research summary on the internet which highlights previous bad practice and may confront the individual concerned. It is important therefore to talk through these sorts of possibilities before including people’s names in any publications.

References


