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# Editorial

Sadly, this is the last edition of the Mental Health and Learning Disabilities Research and Practice journal to be published in its current form. The organisations that have provided funding for the journal since its inception in 2004 are no longer able to do so and it is therefore not possible to continue publication.

The journal's philosophy has always been clear:
> "To disseminate good quality, practice based, research and development in the fields of mental health and learning disability."

It has particularly sought to:
- Support novice and first time authors;
- Provide good constructive feedback to authors;
- Include the service user and carer perspective wherever possible;
- Respect and value diversity;
- Encourage articles that increase the knowledge base and support the transfer of knowledge between policy, research and practice.

We may not always have been successful but, as an editorial board, we believe we have remained true to our objectives of inclusivity and accessibility. However, the need to prioritise the Research Assessment Exercise in academic institutions and changes to NHS research funding mean that organisations are now more firmly focused on achieving publication in high impact journals and investing in bids for research funding.

Despite this, we believe that the journal has played an important role in encouraging researchers, including service users and carers, to publish their work. In its seven year history, the journal has been published fifteen times (including the current edition). Four editions were special editions on the topics of: psychological therapies, learning disabilities, new ways of working, and service user and carer involvement in research. Authors ranged from international researchers to a small number of service users and carers.

The editorial board would like to take this opportunity to thank all those who have contributed to the life and success of the journal including board members, authors, peer reviewers, and, most of all, our readers. A particular note of thanks should go to the journal administrator, Alison Holmes, who has been with the journal throughout its development. The editorial board would also like to acknowledge and thank Virginia Minogue who has provided the main leadership and coordination throughout the life of the journal.

# The Arms of the Infinite?
# The Liability of Mental Health Professionals for the Violent Acts of their Patient

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# The Arms of the Infinite? – The Liability of Mental Health Professionals for the Violent Acts of their Patients

Andy Young

## Abstract

The article reviews the clinical and legal obligations faced by those with responsibility for the clinical management of potentially violent mentally disordered offenders. Responsibility for violent patients is now a mainstream issue for all mental health practitioners who as part of their professional practice will be expected to have at least a working knowledge of the principles and practice of risk assessment and management. With civil litigation growing for health care negligence there is a pressing need to educate mental health professionals about their legal rights and responsibilities towards violent patients.

The primary ethical and legal responsibility of mental health professionals is to their patients. However, the law also requires practitioners to exercise reasonable care in responding to clients' threats against third parties and, under strictly limited circumstances, protect them from harm.

In general, the law does not require workers to warn third parties but permits warnings if the clinician deems them necessary. Case law does not nullify the practitioner's ethical obligation to protect client confidentiality under most circumstances.

**Keywords:** Violence, Risk, Accountability, Law, Ethics, Mental Health Act.

## Background

Before the Mental Health Act 2007, detained patients had a Responsible Medical Officer (consultant psychiatrist) in charge of their care. In addition, there could be several junior doctors. Now there will be a Responsible Clinician in charge of their care, with other Approved Clinician(s) also involved. Neither the Approved nor Responsible Clinician has to be a doctor and the following staff can qualify as Approved Clinicians: nurses, social workers, psychologists, occupational therapists and doctors.

It is currently unclear whether the courts will impose what could be extended liability on Responsible Clinicians. The question is whether mental health professionals should be held liable in negligence when their patients commit crimes. Should this liability extend to victims and their families as well as clients and if a patient is discharged, for how long should a Responsible Clinician remain liable for his or her subsequent behaviour?

Although there is little case law to assist in deciding these questions, there are strong arguments based on legal and ethical principles as well as public policy for limiting the liability of mental health practitioners. Many of them spring from two ethical dilemmas at the heart of mental health law: to what extent should a mental health professional be entitled to restrict the liberty of a patient in the interests of others and to what extent should one adult be responsible for the acts of another? (Adshead 2000; Hale 2010).

## Working with Assaultative Offenders – Clinical Duties

Assaultative behaviours are not just dangerous for the individual; they are also dangerous for other people. Dangerousness here refers not just to the nature of the behaviours but also to the degree of victimisation (Prins 2005). Ethical and legal considerations also take on a

much greater prominence with assaultative offenders (Young 2003). For example, when an assaultative offender discloses a re-offence to a therapist the legal and ethical ramifications are qualitatively different from those involved when an alcoholic or even a drug addict reports a relapse. In the case of an assault relapse, such as threats to injure, there may be a duty of care to inform (protect) the third party at risk.

In terms of global review, the Court of Appeal last considered the duties of mental health professionals in respect of dangerous patients in W v Egdell: it held that practitioners could breach patient confidentiality in notifying a responsible authority of a risk posed by a patient and that they 'may have a duty to do so'. It did not, however, suggest that there was any duty to communicate directly with and protect a potential victim (Adshead 2000). The advice given to mental health practitioners by professional bodies goes no further than this. In the arguably analogous case of a patient with AIDS, both the GMC and NMC have stated that medical and nursing staff can disclose that information to a third party without the patient's consent where there is a serious identifiable risk of transmission to an identifiable victim (Jones 2003; Herring 2010).

## The Law in the United States

The issue was considered by the Californian Supreme Court in the case of Tarasoff v Regents of the University of California (1976). The legal basis for much of the present tort law in relation to a patient's violent actions in the community is rooted in this much-cited case, which established the 'duty to protect' in the US. The basic facts of the case are as follows:

Tatiana Tarasoff was loved by a Mr Prosenjit Poddar, an Indian graduate student studying naval architecture at the University of California. The two young people knew each other, but did not have a close relationship, and it is unlikely that Ms Tarasoff was aware of Mr Poddar's infatuation and the depth of his feelings. Mr Poddar was depressed about his feelings for Ms Tarasoff. During his sessions with a University counsellor he told his therapist that he had fantasies of killing Ms Tarasoff. He also told someone else that he intended buying a gun, and this information was passed on to the therapist, who confronted Poddar about it. The therapist was alarmed and contacted the campus police. They interviewed Mr Poddar who denied any wish to harm Ms Tarasoff. Three weeks later Mr Poddar went to Ms Tarasoff's house and shot her. He pleaded insanity, went to hospital and after two years was released and returned to his native land (Jones 2003).

Ms Tarasoff's family sued for negligence, arguing that the university had failed to protect their daughter and, as a consequence, she had died. The Californian Supreme Court debated this twice having both concerns about the implications for public policy and being advised of professional concerns about patient confidentiality. They decided that there was a duty of care to both warn and protect third parties. The duty to warn should be given where there was an identifiable party at risk. The duty to protect could be carried out by the use of existing mental health legislation for civil commitment, or taking steps to use it.

Since the Tarasoff ruling in 1976 some US states have been willing to give a *wide* interpretation to the duty to protect. In one case, damages were awarded against a doctor when a patient burnt down a farm building, even though there was no identifiable victim, and no warning given by the patient (Simone and Fulero 2005).

Perhaps this is not surprising, considering that community care has had a longer history in the USA, than the UK, that such a legal framework has developed there in relation to violent incidents in the community (Dawson 2010).

## English Law

Technically, these principles could be applied in English Law and the clinical duty *to* warn and protect extended to members of the broader public not just identifiable victims, as it has in some US states. When the English courts come to consider the question, as they surely will now that non-medical staff can take on lead clinical roles under the Mental Health Act, they will have to answer the question relying on the basic principles of clinical negligence: are the Responsible Clinician and patient or victim in a sufficiently proximate relationship, and if they are, are there any reasons of public policy that preclude or limit a duty of care?

It is perhaps instructive to consider the case of Home Office v Dorset Yacht Co [1970] AC 1004. Here, borstal boys who had been taken on a residential outing escaped due to the negligence of the warders. These young offenders then did considerable damage to neighbouring property and the Home Office was held liable for its employees' failure to control the offenders in their charge. Lord Diplock gave as a reason, the existence of a 'special relationship' between the prison officers, their charges and a distinct group of persons who were potential victims.

## Proximity: Responsible Clinicians, Patients and their Victims

In the case of mental health professionals, patients and their victims is there an analogous 'special relationship' sufficient to justify the imposition of liability?

The first, and arguably the most closely analogous case, is that of the detained patient.

Under the Mental Health Act 1983 (as revised by the Mental Health Act 2007), a particular clinician is assigned responsibility for a patient. The Responsible Clinician has a substantial amount of information about and control over the patient and it seems reasonable to expect her or him to take steps to prevent behaviour in foreseeable dangerous ways. However, the question is more difficult when dealing with patients who have been discharged or who remain outpatients. When a patient has recently been discharged there may still be sufficient proximity, especially where the Responsible Clinician has the authority to discharge. Many patients, particularly those with a notable history of offending, are discharged by the Mental Health Review Tribunal or the statutory restrictions on them are lifted by the Ministry of Justice. While these decisions are based on medical and social care reports it is not the Responsible Clinician who orders the discharge and it is questionable whether a 'special relationship' exists in those circumstances.

Similarly, it is unlikely that a court would find a proximate relationship between a clinician and an outpatient but a Responsible Clinician might be obliged to warn the police, for instance, of the threatened risk to an individual by virtue of W v Egdell [1990].

However, it would probably be unreasonable to impose a duty of care on them to control a patient if they do not have statutory power to detain. The extent or size of the class of potential victims to whom a practitioner might owe a duty of care is uncertain. Also, a judge might be reluctant to find a duty of care to a third party if doing so might lead to a conflict of interest for the clinician and force them to choose between a duty of care to the patient and a duty of care to protect potential third party victims (Young 2003). Occasionally the courts have had to decide between opposing public interests and rule on which interest should be dominant and take precedence. The case of Egdell (concerning a breach of confidentiality by a doctor) was upheld on the grounds of public safety. In his judgement, Mr Justice Scott found that Dr. Egdell 'owed a duty not only to his patient but to the public at large'. He was however at pains to point out that 'Only in the most extreme circumstances could a doctor

(or nurse) be relieved from observing the strict duty of confidence imposed on by his relationship with his patient.'

When a patient identifies a proposed victim, the proximity of the relationship may be established, but it is doubtful whether a mental health professional can be held liable in respect of any potential but unknown victim of a patient. Support for this position comes from the decision of the House of Lords in Hill v Chief Constable of West Yorkshire (1988) when it was held that there was not a sufficiently proximate relationship between the police and a class of persons such as 'women' who were the potential victims of the Yorkshire Ripper. Therefore, relatives of victims of the Yorkshire Ripper had no claim against the police for any careless or ineffective handling of the case. The argument that the Ripper's thirteenth victim would not have died but for the negligence of the police investigation was therefore rejected. By contrast in Osman v Ferguson (2000) the court found the requisite 'special relationship' existed between the police and an identifiable victim. In that case a teacher formed an obsessive attachment to a pupil, committed a number of minor acts of criminal damage affecting his family and told a police constable that there was a danger that he might do something criminally insane. Finally, he shot and killed the pupil's father and was convicted and later detained in a mental hospital. Between these two instances it may be possible but quite difficult to identify a class of persons rather than just an individual to whom a duty may be owed, particularly if an attack is seemingly random. Potentially, this reasoning could exclude the health authority's liability.

## Public Policy

The second criterion for the imposition of a duty of care is that it should not be negated by public policy. In Osman, despite the court finding that there was a 'special relationship', the police were not held liable. The court came to the same conclusion in Hill because it wished to avoid the adoption by the police of unduly defensive practices. It took the view that the imposition of a duty would 'not promote the observance of a higher standard of care and might divert resources from the investigation and suppression of crime'. A subsequent application to the European Court of Human Rights (EctHR) identified that this contravened Article 6. While the court appreciated that the rule was in place to ensure the effectiveness of the police, it had not been balanced with the rights of the public.

Public authorities act under statutory duties and their liability has been the subject of a wide range of cases for misfeasance. Since public money is involved in settling such claims it is also inevitable that policy is a major consideration in determining whether or not claims in negligence are possible. The decision will very often rest on the fact of whether or not it is fair, just and reasonable in the circumstances to impose a duty.

In this way the Court of Appeal would not accept that a health authority could be liable for the murder of a child by a psychiatric outpatient in Palmer v Tees Health Authority and Hartlepool and East Durham NHS Trust (1999) Lloyd's Rep Med 351. The facts were that the claimant's child had been abducted, abused and murdered by a psychiatric patient for whose care the health authority was responsible. The patient who had a history of violence, had threatened to murder an unidentified child. The claimant now suffered with psychiatric illness as a result of her child's murder and sought damages for negligence from the health authority, alleging that the defendants had failed to diagnose the real and foreseeable risk that the patient would cause serious injury to the child and failed to provide adequate treatment to prevent him from doing so (Mason 2000). The claim was struck out as showing no cause of action on the basis that the health authority owed no duty of care to either the child or her mother. The Court of Appeal ruled that it was at least necessary for the victim to be identifiable in order to establish proximity. The reasoning is very close to that in Hill.

## Public Policy and the Approved Clinician

Considerations of public policy are equally pertinent for Approved Clinicians who, like many healthcare professionals, are acutely aware of the difficulties associated with defensive health practice (Hurley 2007). Those concerned with the civil liberties of the mentally ill may think it is already difficult enough to secure a patient's discharge without adding to the pressures on practitioners to continue their control over them. Some argue that liability in negligence is a means of shifting the burden of responsibility for the acts of violent patients away from individuals towards health authorities (Samuels 2008). However, in financial terms at least, the victims of crime and their families are provided for by the Criminal Injury Compensation Scheme (CICS).

As for increasing the accountability of clinicians and health authorities, given long-established complaints procedures, recent inquiries and intense media interest (Swinson et al, 2007) it is perhaps doubtful that an extension of tortuous duties would have any significant effect.

The question of whether it is right for a claimant to recover damages in reliance on a blatantly criminal act was considered when the defendant made an application to dismiss the claimant's claim in Clunis v Camden and Islington Health Authority.

Here, the court ruled that the defendant Health Authority had an obvious duty of care 'to treat and to provide aftercare on discharge from hospital' for the claimant who had a long history of mental illness. The Court of Appeal would not accept that this duty extended so far that the defendants would be liable when Clunis stabbed another man to death and was convicted of manslaughter. A party claiming negligence based on an allegation that the defendant caused and/or failed properly to treat mental disorder, could in principle recover damages for self-inflicted harm, and was not precluded from doing so even if the harm resulted from harming others in a criminal manner (Herring 2010).

## Standard of Care

If a duty of care is to be imposed on the Responsible Clinician the next question is what the standard of care might be. The usual Bolam test would require mental health professionals to act in accordance with a reasonable body of medical opinion (Young 2009a). This would involve practitioners carrying out a risk assessment on a patient in accordance with a reasonable body of medical opinion about such assessments and treating a patient accordingly (Woods and Kettles 2009). Legal argument would then centre on what a proper risk assessment should entail.

Currently, there is lively discussion in mental health practice about what form risk assessment should take, and what clinical (and actuarial) factors they should include (Webster and Hucker 2006; Woods and Kettles 2009). There are many risk assessment tools available across England and Wales and those in use vary from NHS Trust to NHS Trust. However, the NHS does make use of standardised risk assessment tools (especially within forensic mental health care services), and some of these tools are used by the Police and Probation Service (Maden 2007).

The Department of Health has issued guidance in this area (Department of Health 2007) and their 'principles and evidence for best practice' emphasise that risk behaviour does not occur in a vacuum, it always has a context and is invariably the result of a complex interaction between individuals and their environments and situations. To assume that dangerousness (or risk) are permanent features is to ignore the significance of context and making such assumptions produces a blinkered view of the patient and greatly oversimplifies the risk

assessment process. Behaviour and emotions need to be assessed and understood in connection with the thought, perceptions and interpretation an individual has about situations, other people and their own behaviour. Consequently, the assessment, reduction and management of risk behaviour should be broad based and multi-modal in its approach and the clinical decision-making process viewed as the central issue, rather than the 'prediction' itself (Department of Health 2007). This does not deny the process importance of attempting to make predictions about behaviour, but combines this with a process of explanation and understanding (Hanson 2005).

Also, non-clinical factors such as unavailability of healthcare records at weekends are probably as significant as clinical matters. Claimants might contend that more should have been done in terms of the information obtained, the variety of sources of information or the length of any period of observation (Samuels 2008). Ultimately it should be possible to establish a clinical standard of risk assessment as there is in the US and Canada (Monahan 1993 and Maden, 2005) and protocols may even be devised. This would put the emphasis on a clinical skill, which mental health care professionals can and do acquire through training and expertise, rather than on the ability to predict the future (Department of Health 2007).

Yet, it is questionable whether this standard of care would require mental health professionals to detain a patient who is assessed as dangerous. The Mental Health Act 1983 (as revised in 2007) imposes no such duty on practitioners. The purpose of the legislation is to allow mental health professionals to detain, not oblige them to do so. The Act was not conceived as a mandate for locking up dangerous people and only imposes a duty on Approved Mental Health Professionals (AMHP) to make the relevant application (Prins 2008). Most importantly, a patient may only be detained if the relevant statutory criteria are fulfilled and danger to others alone is neither a necessary nor a sufficient condition. If a patient has been assessed by an AMHP and doctors in accordance with the Act and is not detainable it would be wrong for both of them and the patient for some further common law duty to detain to be introduced.

## The Chain of Causation

It must be remembered that any violent crimes are committed for reasons other than mental illness – substance misuse or emotional distress are just as significant factors (Woods & Kettles 2009). Consequently, the chain of causation from a patient's assessment to discharge to crime may be so long and convoluted that liability can no longer be imposed on the original mental health care providers.

In such cases, while it may be said that the crime would not have been committed had the patient been in hospital (although it might still have been), the discharge of the patient, negligent or otherwise cannot be the cause of the offence. Where there had been an intervening event, or the chain of causation is long, liability cannot be imposed. Otherwise detention in hospital might be justified solely for the purpose of preventing crime. Even if it can be shown that a patient committed a crime in a state of diminished responsibility it does not necessarily follow that it was caused by mental illness or an associated clinical failure. First, the tests in tort and in criminal law would concern the patient's state of mind at different times and, secondly, the tests themselves are different. For example, it is often the case that a defendant who successfully relies on a defence of diminished responsibility is not subsequently detained under the Mental Health Act 1983 (Hale 2010).

## Conclusions

The mental health practitioner role has expanded and the increased professional autonomy brings increased legal risk (Young 2009b; Young 2010). A proactive and robust approach to

managing that risk is required. Where a patient is known to be violent and is under the supervision and control of the practitioner, or the appropriate authority, in circumstances in which it is reasonably foreseeable that the patient will cause injury should he or she escape, there is a strong argument that a duty of care will be owed to the victim. The extent of any liability based on this principle will of course depend on the exact facts of a case. In other words, it is likely that the Responsible Clinician does owe a duty to patients and their prospective identifiable victims. This duty however, is circumscribed: it may not extend to the whole community or oblige mental health practitioners to control patients they may not lawfully detain or treat. Also, where a clinical duty of care is imposed its focus should be clinical and on the establishment of a standard or risk assessment rather than on the prediction and prevention of crime.

Tarasoff-like scenarios reflect a conflict of public interests between the obligations of mental health professionals to their clients and the public at large. It is open to some doubt whether the courts, today, would seek to extend a Responsible Clinician's legal duty of care to identifiable or unidentifiable third parties. However, they might, if 'the right' case came before the courts. Arguably, community care reforms have vastly altered the 'map of the terrain' and the very nature of mental health/forensic care over the last decade and it could be argued that that the law has not kept pace with developments. Also, there is now detailed guidance for mental health professionals (National Reference Group, 2010) and more sophisticated procedures in relation to risk assessment and discharge that might make it easier for the courts to justify the imposition of a duty.

The main implications of this are fourfold:

First, proper training for lead clinicians is required. Mental health professionals taking on the role of Responsible Clinician must be fully aware of their legal responsibility and all mental health practitioners require education in relation to information sharing and defensible risk decision-making and ensuring the needs and rights of mental health patients (Prins 2005 and 2007). Similarly, the public and the courts also need to be educated about what mental health professionals do as there is a constant risk of violence in society and a large part of it is not due to mental illness or its negligent treatment (Maden 2007).

Second, holding specific mental health professionals liable for all the crimes committed by the mentally disordered will not stop violent offending but may lead to the unwarranted detention and treatment of patients solely because of fears about their dangerousness and a decline in professional morale.

Thirdly, more research is needed to clarify exactly how practitioners balance risk and rights, particularly in complex cases involving 'imposed' recovery. The systemic issues and the value assumptions that health professionals often bring to their interactions with clients needs to be explored further. Not until we have serious debate about such issues will health services fully translate the current rhetoric of collaborative partnership into reality for health professionals and the clients they serve.

Fourth, is it fair for Responsible Clinicians to have to take ultimate responsibility given today's emphasis upon team working and multi-disciplinary decision-making?

The clinical duty to potential third party victims does not necessarily correspond to the professional duty set out in the relevant codes of ethics of the professions or, indeed, the moral duty or moral views that any individual may hold. Case conference decisions also influence the treatment programme, so perhaps there needs to be formal corporate decision-making/governance (with a signed agreement) in certain clinical cases e.g. those involving restricted patients and potential liability to named victims or specific groups of individuals.

Ultimately, the crucial issue might not be whether a possible legal duty is imposed but the perceived threat of legal proceedings and public concern when things go wrong.

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# Up Close and Personal: A Qualitative Study Exploring the Lived Experience of Older Carers

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# Up Close and Personal: A Qualitative Study Exploring the Lived Experience of Older Carers

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## Abstract

This study explored the experiences of informal carers who were aged 65 years and over. It has been estimated that 15 per cent of those aged 65 or over provide some form of informal care in England. Despite a growing literature on the involvement of older people in research, there is a paucity of literature on the involvement of older carers. In this study, older carers were identified via a General Practice (GP) register in one urban medical practice. Data was collected through a series of focus groups, which were transcribed and analysed using thematic analysis. Every carer aged 55 or over and registered with the medical practice was invited to take part in the study. Four female carers and one male carer took part in the study (age range 65-83). Themes that emerged during data analysis included, 1) managing things in an emergency, 2) feeling valued because they took part in the research and 3) the day-to-day reality of living with social exclusion. GP registers provide a valuable tool for identifying older carers who may otherwise be difficult to engage in research. However, persuading GPs to engage with qualitative research may be a challenge.

**Key words:** Older Carers, Informal Care, Qualitative Research, Participatory Methodologies, Carer Involvement.

## Background

The key role older people play in the generation of social and human capital was identified by the former Prime Minister (Tony Blair) in 'Winning the Generation Game' (Performance and Innovation Unit 2000) and in 'A Sure Start to Later Life' (Office of the Deputy Prime Minister 2006). Research by Reed et al (2006) however found that older people continue to be more often consulted, and less often involved, in the decision-making process. This finding echoes earlier research by the Joseph Rowntree Foundation who highlighted that:

> despite the rhetoric of involvement, in most cases the level of involvement of older people (personally in their own lives and collectively in local and in national initiatives) remains low, probably even lower than for disabled people' (Older People's Steering Group 2004: 5).

However, research, including Biggs (2001) identified that, given the right support, older people may have the capacity to contribute to the decision-making processes more effectively than previously thought.

## Patient and Public Involvement

Patient and public involvement (PPI) in health and social care in the UK is a central plank in the development of user-focused services (Local Government and Public Involvement in Health Act 2007). Many different levels and types of user involvement have been identified, including involvement in the commissioning process, quality checking, evaluation and development (Boote et al 2010). Running parallel to the involvement of users in services is the need for PPI in the research process. The UK government, past and present, is committed to the notion that 'Research is essential to the successful promotion and protection of health and wellbeing, and also to modern, effective health and social care services' (Research Governance Framework for Health and Social Care 2005: 2). Over the past ten years, while

some progress has been made towards the involvement of older people in research (Tetley 2010), the involvement of particular groups, including older carers, remains problematic.

An initial search of the literature identified a number of papers outlining the difficulties faced by older carers of people with dementia (Lewis 1998), mental illness (Murry and Livingstone 1998) and learning disabilities (Maggs and Laugharne 1996). However, only one study, by McGarry and Arthur (2001) focused on the needs of older carers *per se.* A literature review by Fudge et al (2007) indentified thirty studies involving older people in research using participatory methodologies. Participatory methodologies is usually taken to mean that people are involved in advising on a research project, assisting in the design of a project, or in carrying out the research, rather than being viewed as data repositories. None of the studies identified by Fudge (2007) involved older carers as a discrete group. Despite a growing number of government initiatives and publications designed to end discrimination against older people (Department of Health (DH) 2001; Phillipson & Scharf 2004; Scharf et al 2005; DH 2006; DH 2007) it appeared that the invisibility (and therefore vulnerability) of older carers remained problematic. This current paper addresses this gap in the literature by reporting on a study that involved older carers in the development of a research topic, in the confirmation of the study's findings, editing of the draft report and in the dissemination of the results nationally and locally (Parker 2010).

Research by the Social Care Institute for Excellence found that:

> 'society often disables older people simply because they are old and by assuming they cannot perform certain tasks' (Carr 2004: 5).

This paper argues that older people in general and older carers in particular have the knowledge, skills and expertise to be involved in all types and in all levels of research. In order for this to happen, however, researchers need to build the necessary time into research proposals from the beginning of the research process.

## Methodology

### How the Literature was Searched

Several literature searches were undertaken during the course of the study between 2006/07 and again prior to publication of this article. Databases searched include, ISI Web of Knowledge, Bio-Med Central, Blackwell Synergy, WileyInterscience, British Nursing Index, Proquest Nursing Journals Database and Google Scholar. Search terms included (but were not restricted to) research involving older people, older carers, inclusion, exclusion, poverty and elderly people, qualitative case study, ethical issues and participatory methods.

### The Conceptual Framework

The world of older carers is so under-represented in research that exploring any aspect of their lives would doubtless reveal a valuable seam of rich, deep and original insights. I was very aware, however, of the necessity to focus on just one aspect of their lives. So, for the purposes of this study, I did not focus on the social processes involved in sustaining older carers, for that aspect of the case would be better served by utilising a grounded theory approach to data collection and analysis (Glaser and Strauss 1967). Neither did I present a statistical analysis of event occurrence, for that would be better served by a study with a positivist slant (Yin 2003).

Instead, I focused on how each older carer perceived and interpreted their unique experience in a range of situations, which I hoped would present the reader with multiple views or

interpretations of the described experience. As advocated by Stake (1995) an interpretivist approach to data collection and analysis was adopted. This encouraged data triangulation through the use of multiple methods of data collation (Morse & Field 1996; Yin 2003).

## Sampling Framework

Since so little was known about the work and world of hidden carers, and my goal was to enable older carers to reveal their hidden world, revelatory case sampling was used (Teddlie and Yu 2007). Moreover, I believed the best way to gain an in-depth understanding was to engage with the carers directly. In the first instance, I wrote an introductory letter to all GP medical practices in the town. Only one GP medical practice agreed to take part. In order to recruit enough participants, I invited all carers aged 55 and older to participate in the study. I then set up an introductory meeting at the GP medical practice. This meeting was successful in recruiting five older carers to the study. At the time of the study, older carers were aged 65-83 and had informal caring responsibilities for their spouse (1), adult child with mental health problems (1) and adult child with learning disabilities (3). Demographic data for the older carers can be found in table 1.

**Table 1**

| Biographical data for the older carers in the study | | | | | |
|---|---|---|---|---|---|
| | **Carer 1** | **Carer 2** | **Carer 3** | **Carer 4** | **Carer 5** |
| **Gender** | | | | | |
| Male | X | | | | |
| Female | | X | X | X | X |
| **Age range** | | | | | |
| 60-70 | | X | | | |
| 70-80 | | | X | X | X |
| 80-90 | X | | | | |
| **Relationship to dependant** | | | | | |
| Adult child with moderate learning disabilities | | | | | X |
| Adult child with Profound and Multiple Learning Disabilities | | | X | | |
| Adult child with mental health problems | | X | | | |
| Adult child with Down's Syndrome | | | | X | |
| Wife with Alzheimer's Disease | X | | | | |

**The Research Setting**

In qualitative research, the selection of the research setting is of particular significance. Morse and Field (1996) for example, pointed out the importance of visiting the research setting before the development of the proposal to gain the permission and cooperation of staff. With this in mind, I visited several settings before making my final choice. Older carers could not be involved in making this decision, as this had to be decided before I submitted the proposal to NHS research governance and research ethics committees. After much deliberation, I decided to hold the focus group meetings in a local Church community hall. I did this for a number of reasons:

1. The Church was near to the town centre and conveniently situated on the main bus route.

2. All of the facilities were on the ground floor with good access for people with disabilities.

3. A lunch club was held every Thursday, providing a tasty lunch at a very reasonable cost.

4. There was a separate meeting room where focus group members could meet in private after lunch.

5. The meeting room was available at no cost (the study was unfunded so this was important to me).

6. Staff at the Church were extremely friendly and sympathetic to the aims of the study.

Of particular significance to me was the provision of a hot midday meal in a relaxed setting. I believed that creating space for focus group members to get to know each other socially would be pivotal to the success of the study. Stewart and Shamdasani (1990) suggested a number of ice-breaking activities to help put people at ease before the start of a focus group meeting. However, I wanted to do more than just put people at ease. I wanted to demonstrate my appreciation of the commitment older carers had made to the study (by providing a tasty lunch and an opportunity for some social chit-chat), and I wanted to get them in the mood for story telling (Jackson and Esse 2006).

**Data Collection**

In this study data was collected via four focus group meetings, four research diaries completed by the older carers and reflective notes, field notes, minutes from meetings and memos. Two of the four focus group meetings were audio recorded. One was fully transcribed and one was partially transcribed. Copious field notes were made during and after the two meetings not audio recorded. All data produced in this way was typed up and sent to the older carers for editing and amending as necessary.

**Data Analysis**

Thematic analysis was used as a conceptual framework to analyse the data (Miles & Huberman 1994). Analysis (or data reduction) took place on eight levels:

1. Older carers completed a research diary. These were completed at home and then read through at the next focus group meeting. At the focus group meeting, older carers added anecdotal reflections that added context and significance to diary entries.

2.  Older carers identified themes from the research diaries and these were used as topics for discussion at the next focus group meeting.

3.  At the next focus group meeting older carers expounded upon the previously identified themes, offering many examples to illustrate their points. This meeting was audio-recorded.

4.  At the third focus group meeting, older carers went through the typed up manuscript of the previous meeting sentence by sentence, marking with a highlighter pen anything they found to be significant. This meeting was also audio-recorded.

5.  As we worked through the manuscript, older carers expanded upon why something was being highlighted and in this way, further revelatory insights were added to the manuscript.

6.  I then went through the field notes, memos and typed up manuscripts and coded the main themes into overarching categories. After a discussion with older carers the final themes were agreed.

7.  Literature (grey and mainstream) from the fields of health, social care, education, psychology and business was searched and used to provide context for the study's identified themes.

8.  Older carers read through a draft of the completed report and made a number of important points, which are discussed later in the paper.

**Discussion of Themes Identified by the Older Carers**

**Social Exclusion**

Scharf et al (2005) identified that the death of a partner, the onset of chronic ill health and the assumption of caring responsibilities are all risk factors in older people becoming socially excluded. Although social exclusion is not always synonymous with social invisibility, in the case of older carers, it would appear that as their vulnerability increases (in terms of decreasing family networks, increasingly poor health and the continuation - or assumption - of caring responsibilities) the cloak of social invisibility is wrapped ever more tightly around them.

The purpose of this study was not to directly ask older carers about their experiences of feeling socially excluded. However, even a cursory reading of the research diaries and transcripts from the focus group meetings demonstrated that older carers were at risk from social exclusion on multiple fronts. For example, older carers in this study had serious health problems ranging from insulin-controlled diabetes, advanced heart failure and osteoporosis. This meant that for some, mobility was a constant challenge and when combined with exhaustion posed serious threats to their health. This often meant that they were too tired to make the effort to socialise. And when they did get a break they liked to spend it quietly, contemplatively.

Older carers identified that balancing the need for companionship against the need for solitude was a daily challenge. On the one hand, because conversation at home was often limited to giving directions or answering the same questions day after day, older carers looked forward to chatting with friends, having what Mick called 'a proper conversation'. But, paradoxically, although the need for companionship was strong, the busyness of their everyday lives made them long for a quiet space to re-charge their batteries.

**Vignette 1**

Margaret reads out her diary from the previous week. On day five she wrote about one activity:

> Went to Café for lunch. Thoughtfully, Margaret added, that she really needed this time of just sitting, alone (but in a crowd). Somehow being alone in the Café, watching everyone pass by was different to being alone at home. Not so lonely. Margaret remarked how she even got a little irritated if someone she knew came and sat with her, as this was much needed private space. Everyone nodded in recognition of this and shared how they too needed this 'private time'.
> Research diary Margaret, Day 5.

A number of researchers have written about the danger of consultation/research fatigue with easily accessible groups of older people (Butt & O'Neil 2004; Holland 2005). Sin (2004, cited in Holland 2005: 6) for example, noted how community organisations are often targeted by researchers that 'have swooped in, gathered their data, and left nothing of clear benefit to the researched'. The 'researched' (even in these easily accessible groups) however are only rarely involved in actually doing the research.

Older carers could in no way be described as an easily accessible group, so there was no danger of them experiencing consultation or research fatigue. In fact, Mick shared a story of how (just a few days before the research study began) a market researcher knocked on the door of his home and before administering the survey, asked Mick if he was working or retired. Upon finding out that Mick was retired, the market researcher said he was only interested in the views of the employed and was therefore unable to ask Mick any further questions. The survey was about the possible development of a large superstore in the town in which Mick lived – a development to which there was much local opposition. Surely this was one issue that affected every community member? It would seem that nothing much had changed since Carr's (2004) finding several years earlier that older people were excluded from just about everything, simply because they are old.

**The Value of Involvement**

Older people want to be involved in research, but they are clear that they want to be involved in research that makes a difference (Reed et al 2006). This was a view shared by older carers taking part in this study who noted that the work they were undertaking was novel and could have far-reaching consequences in their small community.

> This is pioneering, isn't it?...hopefully a lot of good will come, more and more'
> Transcript of focus group meeting, Alice.

Although there was little doubt in my mind that older carers – because of their extensive life experience – had the knowledge, skills and expertise to act as co-researchers, I needed to convince them of that. Using naturally occurring activities, such as research diaries and focus group meetings to collect the data proved to be instrumental in enabling older carers to see how they could contribute towards achieving the aims of the study. During the study it came to light that this was the first time anyone had asked the carers to document their day-to-day life. The following quotation illustrates how it was the 'everydayness' of the research tools that rendered them easy to use and how being involved in the research activities made carers feel valued.

> The atmosphere, the down-to-earthness of it, how we described our daily life, our daily working…I've never been asked to do that before…we weren't numbers

> any more, we have a rightful place in this life.
> Focus group meeting transcript, June.

This and other comments made by the older carers were hauntingly reminiscent of the comments made by Frantz Fanon in his exposé of the damaging effects of colonialism and of how he felt when at last his personhood and humanity was (albeit) temporarily valued, 'At last, I had been recognised, I was no longer a zero' (Fanon 2003: 69).

Older carers recognised the transformative effect that being involved in this research study had had on their lives saying,

> June
> …you've given us a name, you've given us a place we never had before [to other carers] do you feel that?
>
> Alice – in response
> Yes, especially as an older parent
> Focus group meeting transcript, p.3.

That the older carers managed to attend almost all of the research meetings was testament to the commitment they showed to the research study. Several of the older carers experienced traumatic life events during the period of time the focus group meetings were running, but despite this, their commitment to the research was unwavering. That unwavering commitment is poignantly illustrated in the vignette below.

## Vignette 2

It was lunchtime and focus group members were chatting together over lunch. The room was noisy and full of hustle and bustle. Threading his way through the crowd towards our table, I spotted Mick and gave him a cheery wave. He was running late, but it didn't matter, lunch was a relatively leisurely affair. The work of the focus group started after lunch. Following closely behind Mick was a woman I hadn't met before; intuitively I knew it was Mick's wife. This was unusual as Mick's wife usually attended a day care facility on Thursdays for people with Alzheimer's disease.

> Mick came up to me and said apologetically:
>
> I'm really sorry, but Marie was too poorly to go the day centre today. I couldn't leave her at home on her own and I didn't want to miss our research meeting, so I've brought Marie along. I hope that's alright.
> Researcher memo, p.1.

## Managing Things in an Emergency

Research by Carers UK (2005: 2) found that 'The very thought of having an emergency causes anxiety for many carers'. The issue of what to do when things go wrong was a constant challenge for older carers in this study. The reality of how hard it is to respond to an emergency was brought into sharp focus by the comments of the older carers who gave numerous examples of when they had to put their own lives (and health problems) to one side, in order to focus on the person they cared for. Trying to avoid situations arising in the first place was a priority for everyone.

Lisa for example, a carer in her mid-sixties, supports her daughter (Mary) who has enduring mental health problems. Lisa's daughter monopolises her time during the day and late into the

evening, to the point that Lisa will restrict her own activities in order to reduce the likelihood of her daughter becoming angry or upset.

> I can't do anything, really. I mean, if Mary had decided that…it wasn't good for her, or good for me, something would have been arranged so that I wouldn't have been able to come [to the research meeting]…It's easier for me to, sort of, play along with her than to say, I am doing this, that and the other, because, I wouldn't know what I'd find when I got back home…
> Focus group meeting transcript, Lisa.

For other older carers the pressure of knowing there is no one else around to look after the person you care for, means that their own health can become seriously affected before they will seek help (Carers UK 2005), not surprisingly, fighting exhaustion became an everyday battle.

> Jack's new wheelchair is not as easy as I thought…We are going for a walk after lunch as I need to get used to Jack's chair. I feel very tired, would rather go for a lie down, but not possible.
> Research diary, Margaret, Day 4.

As illustrated in the following story, becoming ill unexpectedly can have disastrous consequences. Mick's wife Marie was diagnosed with Alzheimer's disease while he was undergoing inpatient treatment in hospital. Unable to cope without him at home, Marie had to be detained under the Mental Capacity Act (1983) for the duration of Mick's treatment (12 weeks). Both Mick and his wife found the experience very distressing.

> She went bonkers, she really did go mad. She tried all the hospitals in the north to find out where I was, of course they wouldn't tell her anything. Eventually, she was sectioned and put into hospital.
> Focus group meeting transcript – Mick.

Carers UK (2005) have identified a number of strategies that need to be in place to support carers when they face emergency situations like this:

- Details of who to contact in an emergency in the form of a key fob or similar
- Training on how to care effectively
- Good advice on what is already available locally
- Information on emerging technologies, helplines, alarms, detectors, automatic switches, etc.
- Ensure carers are better informed about their rights/benefits
- Emergency plan in place.

Provision of these vital services however remains patchy across the country. Carers in this study reported that even in situations where support could be pre-planned, what was offered was often not the right kind of support and sometimes it came too late, or not at all.

> Often they say there's help available, but often it's just not the type that you want…it all looks good on paper, because there's respite care and all that, but sometimes it has to be arranged months and months ahead…if there was an emergency and you had to go somewhere, or even if you were rushed into hospital, you wonder where they're going to go.
> Focus group meeting transcript – Alice.

## Ordinary Spaces as Research Settings

Miles and Huberman (1994) attached so much importance to the management of the research setting that they suggested including a room-plan in the appendices of the research report. Richards (2005: 24) on the other hand talked about the setting in terms of '…entering the field' and the requirement upon the researcher to map the physical, social and cultural terrain. I spent a lot of time thinking about these issues, as I was very aware of the necessity to provide a safe space for older carers to share their stories and for me to conduct my first 'real' research study. I thought my efforts to map out the 'physical, social and cultural terrain' had gone mostly unnoticed by the older carers, however, as the next vignette illustrates, they understood my game plan, perfectly.

## Vignette 3

The issue of keeping everyone 'on task' is a prickly one. For instance, reading the diary entries aloud prompted the reader to set the entry in its wider context – so that it made more sense to the listeners. Often these diary entries prompted other carers to retell other closely related stories, adding depth and richness to the original story. However, stopping these digressions when they become more than once removed from the original, proved tricky. This was noted by the carers themselves who assumed a self-moderating role by saying

> We can only talk about things like that when we are over there (pointing to the previously food-laden table), once we come over here (indicating the circle of chairs) we have to concentrate on what's important to the research.
> Focus group meeting – researcher field notes.

## Reflections on the Research Tools

If older carers had been involved from the very beginning, it is likely that the focus of the study may have been very different. I write this because carers struggled with the idea that their everyday lives were interesting and it was not until the diaries were read aloud at the first focus group meeting that they began to see value in what they had written. A reflective and appreciative silence followed the end of each diary reading and the reader often used this time to regain their composure or add any further insights/comments.

For me, hearing the diary entries read aloud was a very powerful and humbling experience. I was very aware of the privileged nature of the information I was hearing and of the effect that reading the diaries had on carers. While the diaries were being read, everything in the room seemed to recede into the background, except for the soft voice of the reader. It had the same impact on listeners as 'fly on the wall' documentaries do on television viewers, except more so. This was a real person (someone we knew), telling their real story, detaching from the experience was not an option. In a way, we became part of the re-telling of the story (Frank 2000). It was without doubt an intensely emotional experience for both the reader and the listener. Would the same impact have been achieved if I had read the diaries as I had originally planned? I don't think so. Also, I think the study was immeasurably enriched by the inclusion of the anecdotal comments added in along the way as memories from earlier times rose to the surface, strengthening the weave of the story.

Asking carers to complete the research diaries at home had a number of benefits. For example, there was no pressure to complete the daily entries at a certain time of day, or even in a particular format. Carers wrote what they could, when they could. However, I presumed that if carers were uncertain of what they had written that they might ask for help from family of friends. Without exception, however, carers had limited access to outside friendships and family members often lived some distance away. Also, I had not bargained on the fact that

even though carers knew the diary entries would be shared with other carers, they wrote candidly on deeply personal issues. That the diaries were able to capture both the public and private lives of the carers was picked up by Alice who revealed that she had never talked about her day-to-day life with her daughter who had learning disabilities – not even to her closest friends.

> And we can say to you [the researcher], and put it down, when you couldn't to your friends because they know you, and you wouldn't dream of talking that way really…   Focus group meeting transcript, Alice.

## Ethical Issues

Doing research with older carers involves thinking through a range of ethical issues, such as the use of inclusive language and materials, appropriate research tools and training for their use, involvement in the research process and many other ethical challenges. The importance of tackling these issues was obvious, even to me - a novice researcher. However, the more subtle issue of the power of the researcher over the researched was not so obvious, nor easy to navigate. Price (2002: 273) concerned about the issue of researcher power pointed out 'Appropriately briefed respondents have power over the level of responses they decide to offer'. In an attempt to 'appropriately brief' the older carers, I followed the recommendations of Hanley et al (2003) to included them in as many elements of the study as possible, but the fact remained that it was I who set the research agenda, not the older carers.

Permission to conduct the research in the NHS was granted by the Local Research Ethics Committee, the NHS research governance committee and the local Primary Care Trust.

## Limitations of the Study

When I initially planned the involvement of older carers in the study, I had hoped to facilitate at least five or six focus group meetings. However, due to the length of time it took to negotiate NHS ethics, some scaling back occurred on the level and types of involvement that older carers could choose to take part in. Moreover, due to time constraints, it was not possible to facilitate the in-depth training sessions on research methods that older carers would have needed in order to take part in the study at a deeper level. Although time was taken at each focus group meeting to explain the research process and what steps we needed to take in order to move on to the next stage in the study, it was by necessity only a brief introduction to what is a very complex process.

Also, because older carers could not be involved in the development of the research proposal (for this had to be agreed by the research ethics and governance committees before I could approach the older carers), I did not always ask the right questions. For example, when they reviewed and edited the draft report, older carers felt it was somewhat lacking in demographical and biographical data. Older carers felt that the study would have been enhanced by the inclusion of a brief 'pen picture' of each older carer and their dependent, as this would have provided a richer context for their subsequent stories. Older carers also identified that the inclusion in the appendices of a complete list of all the issues raised by them, together with their suggestions for overcoming them, would have been very useful.

## Conclusion

In the UK today, there are numerous ways in which older people can influence decision-making within the statutory, independent and voluntary sectors. Despite this however, older carers remain one of the least consulted and least included groups in research, policy and service development. In this paper we argue that using participatory research with vulnerable

groups such as older carers has the power to be emancipator and, although not without its difficulties, emancipatory research is, according to Lynch, (1999: 41) '…analytically, politically, and ethically essential if research with marginalised and socially excluded groups is to have a transformative impact'. Older carers in this study experienced something of that transformative impact and were eager to be involved as much as their busy schedules allowed them to be.

## Acknowledgements

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# Body Mass Index at a Medium Secure Unit:
## A Four-Year Service Evaluation

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# Body Mass Index at a Medium Secure Unit: A Four-Year Service Evaluation

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This study investigated changes in body mass index (BMI) in male patients at a medium secure unit (MSU) and the subsequent effects of several healthy initiatives over a period of four years. Data was collected from 2005 to 2009 and BMI was calculated on admission and subsequently at least once a year.

## Results

The average BMI increased markedly over the years. A significant number of patients shifted from being overweight to clinically obese. Weight gain occurred mostly in the first year of admission and in most patients efforts to ensure a healthier lifestyle were unsuccessful.

## Clinical Implications

The physical health of patients in secure units needs to be prioritised and healthy lifestyle choices maximised, particularly in the first year following admission. Obesity management requires a person-centered approach, but a pragmatic shift in attitudes, of both patients and staff, towards calorie intake is also required.

**Key words:** Schizophrenia, Weight gain, Secure units, Obesity, Antipsychotics, Body Mass Index.

## Introduction

It is well established that excess body fat significantly increases morbidity. Body mass index (BMI) is an easy, cheap and non-invasive means of assessing excess body fat (National Obesity Observatory 2009). Bjorntorp (1993) has termed the current obesity epidemic as 'civilization syndrome', implying that the positive energy balance (i.e. more calorie intake and less exercise) is dependent on the modern urbanised environment of physical inactivity, stress, smoking and alcohol consumption.

The Health Survey for England (2004) showed that only 29 per cent of the adult male population had a BMI in the desirable range of 20 to 25. 42 per cent on the other hand were overweight (BMI= 25 to 30) and 23 per cent were obese (BMI ≥30). In addition, almost 1 per cent had a BMI of 40 and above. The survey also revealed that between 1993 to 2004, the number of individuals classed as obese had almost doubled.

Obesity is associated with significant morbidity, including hypertension, ischaemic heart disease, type 2 diabetes, dyslipidemia and certain malignancies (Newcomer 2005).

A diagnosis of mental illness has also been associated with weight gain. This is particularly marked in patients suffering from schizophrenia (Goethelf et al 2000).

Antipsychotics, particularly atypicals, such as clozapine, risperidone and olanzapine, used in the treatment of psychotic illnesses such as schizophrenia, have been associated with weight gain and the development of metabolic syndrome (Newcomer 2000; Leadbetter et al 1992; Tadger et al 2008). This is a condition characterised by weight gain (central obesity), hypertension, dyslipidemia and insulin resistance.

The National Institute of Clinical Excellence guidelines (NICE Obesity 2006) recommend multi-component interventions for weight management. This includes increasing physical activity, improving eating behaviour and quality of diet and reducing energy intake (calorie restriction).

Medium secure units (MSU) provide care for relatively long-stay patients in a highly regulated environment. Patients in MSUs are relatively inactive and have access to high calorie food.

This service evaluation aims to establish trends in weight gain among inpatients at an MSU and the effects of several public health interventions over a four year period.

## Method

The hospital is a 60 bed medium secure unit that admits males between 18 and 65 years with a primary diagnosis of mental illness (predominantly schizophrenia).

On admission all patients have a thorough physical assessment that includes height and weight measurements, general and systemic examinations, baseline blood tests and review of any co-morbidities. In the current study we chose to focus on BMI and therefore elected not to use data from the other parameters.

In this study, we set out to evaluate the management of physical health of adult inpatients on our unit. We investigated one specific aspect of this service provision, i.e. whether all inpatients had their weight and BMI measured on admission and at least once yearly subsequently. All consenting inpatients were weighed. However, this did not always cover the whole inpatient population as some patients either refused to participate or were too unwell to be included in the study. One of the authors (SB) kept a record of all patients having had a physical health review and measured the weight and calculated their BMIs at least once every year. The staff on the ward took consent from patients before they were weighed and documented it in the notes.

Following initial weighing on admission, patients were weighed at least yearly until the end of the study in April 2009. All data collected were then anonymised and entered into a secure database. Statistical analyses, including descriptive tests, were performed. The findings were presented to peers at the local clinical governance meetings. The clinical implications of the study were extensively discussed and recommendations for improving the service were put forward. These proposals were implemented in subsequent years and their impacts evaluated.

## Results

## Population, Duration of Stay and Medication

The unit occupancy and inpatient population varied at the different sampling points. In August 2005 we were able to record data from 52 patients, 40 in February 2006, 44 in November 2006, 52 in July 2007, 51 in February 2008 and 46 in April 2009. The variation is also partly secondary to refusal to consent and inability to participate due to severity of illness at the time. The unit admits male patients only. 94 per cent were white British, 4 per cent Afro-Caribbean and 2 per cent Asian in origin

The overall mean duration of admission was 28.7 months. 31 per cent of patients had been inpatients for more than 26 months and a further 17 per cent had been in hospital for more than 48 months. This represented the general trend at the unit and was not specific to the

study period. The samples at each point were somewhat different as some new patients were admitted whilst others were discharged through the four year course of the study. There were only nine inpatients who had been there for more than four years and hence were represented in each study cycle. Therefore, the patient sample was somewhat different at the end when compared to the beginning.

The vast majority of patients were prescribed regular atypical antipsychotic medication. 37 per cent were on clozapine tablets, 14 per cent on risperidone depot, 12 per cent were on typical antipsychotic depot (zuclopenthixol, flupentixol, fluphenazine, haloperidol), 11% on risperidone tablets, 10 per cent on olanzapine tablets, 9 per cent on quetiapine tablets, 7 per cent on aripiprazole tablets, 5 per cent on amisulpride tablets and the remaining 3 per cent were on either haloperidol or sulpride tablets. 4 per cent of patients were not prescribed any antipsychotics. Up to 11 per cent of patients were on two or more antipsychotics simultaneously.

## Change in Body Mass Index (BMI)

BMIs of patients on admission are compared to the general male population in Figure 1. The 'BMI on admission' in this graph represents the average BMI of all the newly admitted patients (n =111) over the course of the study.

There is a wide range of patient weight change over the duration of the study, varying from - 8.5kg (weight loss) to + 65kg (weight gain). However the mean BMI at each sampling point exceeds the mean BMI of the general population such that a significant percentage of patients at each sampling point are clinically obese (BMI ≥30).

Moreover, there is a net increase in the number of overweight and obese patients at each sampling point and a significant number of patients shifted from the overweight to the obese category (Figure 1). 51 per cent of the all the inpatients (n =111) weighed over the course of four years gained an average of 14.1 kilograms (range = 4kgs to 38kgs) in the first year of their admission to the unit.

## Figure 1: Weight Categorisation by BMI
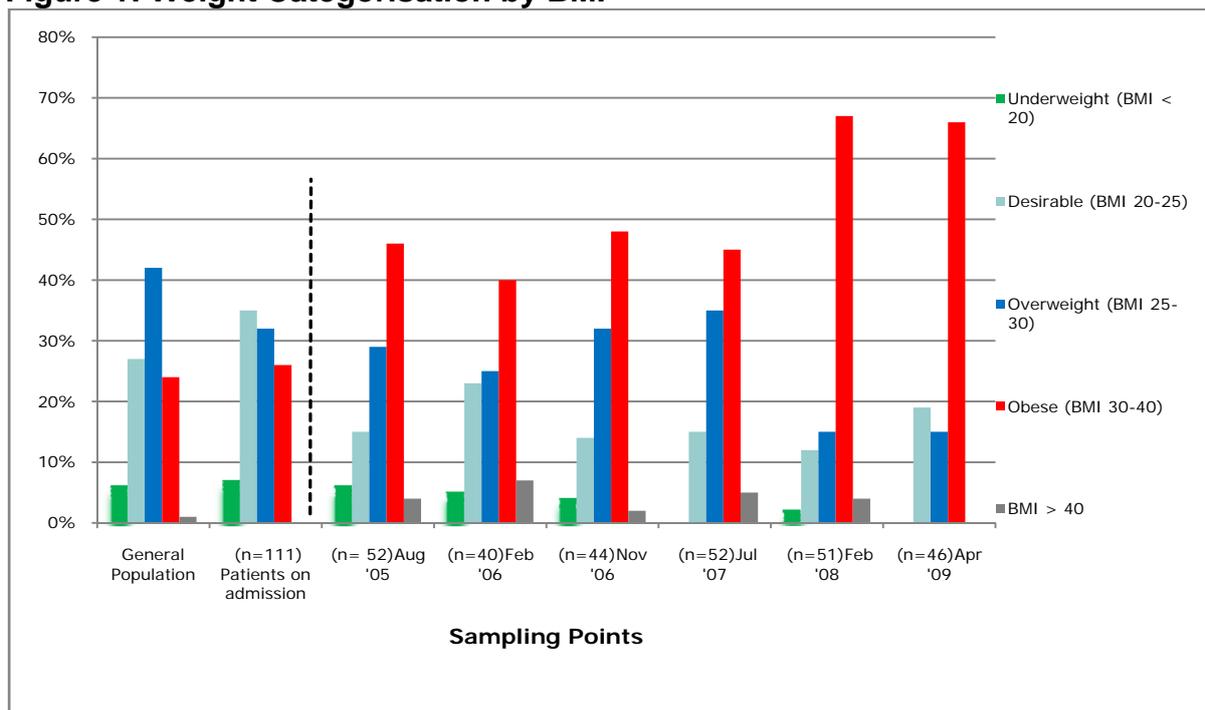
It appears that the most rapid increase in weight occurs in the few months following admission after which there is little variation. Subset analysis of a small sample of five patients, who were admitted around the same time (August - October 2006) and followed for approximately three years, shows that the steepest rise in weight gain (mean increase in BMI = 10.2) occurred in the first 12 months following admission. The weight gain of these patients has yet to plateau although all of them were already clinically obese in the most recent analysis.

Admission data for a group of patients (2009 cohort, n=46, mean duration of stay 23 months) was retrospectively reviewed for changes in BMI (Table 1). The data confirms weight gain over duration of hospital stay.

**Table 1: BMI changes in the April 2009 cohort (n=46)**

| BMI | Mean (*s.d*) | 95% CI |
|---|---|---|
| Admission | 27.6 (5.31) | 26 – 29.2 |
| April 2009 | 30.6 (5.05) | 29.1 - 32.1 |
| Net Change | +3.04 (3.88) | 1.89- 4.19 |

BMI - Body mass index
s.d. - Standard Deviation
95% CI - (95% Confidence Interval)
N - number of patients

**Non-Pharmacological Management of Weight Gain**

Between 2005 and 2008, as the study progressed, interim results were discussed at clinical governance meetings at least yearly. In response to our findings, the unit promoted hospital-wide public health and individual care plans between 2006 and 2009, aimed at addressing the high rates of obesity.

A plated meals service to reduce variation in portion size was introduced. There was also a promotion of healthier options on the hospital's catering menu and in vending machines. Inpatients therefore had access to healthier foods with less energy contents (such as fruits and vegetables). The vending machine items were also replaced from high calorie food to those with fewer calories and less energy (such as whole-meal grain bars, diet soft drinks etc.).

The ordering of high calorie take-away foods by patients was limited to once a week (prior to this study patients could order take-away foods as often as they wanted to). Limits were also imposed on foods introduced into the hospital via carers and patients going on shopping trips.

Finally, healthy living groups were set up to promote healthy dieting and exercise. Patients were encouraged to attend these groups, however few did.

Despite these initiatives, there was a steady increase in patients' weight in each study sample. The most substantial rise in mean BMI occurred between July 2007 and February 2008. This may have been related to the introduction of a hospital-wide smoke-free policy in April 2007.

**Figure 2: Mean BMI Following Healthy Living Initiatives**

## Discussion

Admission to a medium secure unit can possibly result in weight gain for patients. The causes of weight gain in a relatively closed institution are probably multi-factorial in origin, reflecting restricted physical activity, the ready availability and consumption of high calorie food. Other causes not incorporated in the study may be illness-related (e.g. negative symptoms of schizophrenia), medication-related (e.g. sedation and weight gain due to antipsychotics), age-related (older people are more likely to gain weight) and/or ethnicity-related. These associations could have been explored further and are being considered for future projects at the unit.

Smoking cessation is known to be associated with weight gain (Matsushita et al 2010; Munafo et al 2009) and in the course of our study a smoke-free policy was introduced in 2007 which in all probability contributed significantly to the subsequent peak in weight gain observed.

Weight gain in individuals with mental disorders, can deleteriously affect medication adherence and rate of relapse (Weiden et al 2004). These consequences of weight gain can be prevented through dietary modification and physical activity, which are basic and essential components of a healthy lifestyle programme.

We found that limiting calorie intake was difficult to achieve at the unit. Initiatives aimed at curbing weight gain were resisted by many staff and patients. They were criticized as being punitive, restrictive and denying choice to a patient population with restricted liberty. Attempts to reduce calorie intake across the unit as a whole or through targeted care planning thus proved unsuccessful.

Implementing lifestyle changes are always tough to accomplish. It is therefore, not only important to assess the willingness, readiness and motivation of the patient to change but we also need to encourage healthy lifestyle for staff working within such units to help and create a healthier ethos. Education for patients and staff alike about the hazards of obesity may be the first and most important step in this process.

For individuals who are overweight or obese, reduction in weight is more likely to be successfully achieved by setting realistic targets for weight loss (0.5-1 kg/week), providing pragmatic options for physical activity and constantly encouraging healthy eating in general i.e. decrease calorie intake (NICE Obesity 2006). There is also a role for motivational interviewing which helps patients have a healthy dietary intake and improve involvement in physical exercise (Marley et al 2011). It works by highlighting and then helping them to resolve their ambivalence towards a healthy lifestyle.

Weight management and fitness programmes can help achieve reduction in BMI and waist size in a high secure environment (Cormac et al 2008). With regards to antipsychotic induced weight gain, drugs such as clozapine and olanzapine can be introduced gradually in order to minimise dose-dependent metabolic side effects (Simon et al 2009). Alternatively, agents such as Metformin may also have a role to play in the management of antipsychotic induced weight gain (Wu et al 2008). More research is needed to help us understand the role of established anti-obesity pharmacological interventions such as Orlistat and Sibutramine in our patient group (NICE Obesity 2006).

The study population had a mean BMI comparable to the general population at the time of admission and gained weight despite regular monitoring and healthy lifestyles interventions. This demonstrates that sometimes *en-masse* policies are not able to cater for individual needs. Any future policy making should incorporate person-centred care, taking into account individual needs and preferences.

Secure units are 'obesogenic' environments and this has important long-term implications for the physical health and emotional well-being of patients. Individuals, who become overweight in secure units through lack of physical activities and healthy food options or as a result of treatment with antipsychotics, could potentially hold the hospital liable for failing to protect their physical health.

The legal and ethical issues surrounding the desirability of additional restrictions on calorie intake for patients in secure units are complex. An increasingly risk averse culture has led to more paternalistic restrictions in certain areas, such as smoke-free or child visiting policies, whereas more liberal attitudes to food consumption prevail. Hence, we need to first build consensus amongst mental health policy makers on this issue and develop clear national guidelines targeting obesity in general and in particular for patients who have gained excessive weight secondary to their clinical management.

Should long-stay institutions adopt a more assertive public-health approach to inpatient obesity? This would entail careful design of menus, ensuring nutritional balance whilst setting limits on calorie intake, combined with the imposition of strict curbs on foods brought into the unit. At the same time these institutions would be obliged to provide a range of accessible physical activities and health promotion as part of general rehabilitation.

Some patients may not wish to consume healthy foods or engage in a healthier lifestyle and if they have capacity with regards to these decisions, it could be argued that we have to respect them, however unwise they may be. However, we also have a duty to look after individuals under our care holistically, ensuring that both their physical and mental health needs are met.

A change in culture and attitude of both staff and patients towards excessive weight gain may hold the key to winning the 'war on obesity' in secure units.

## Clinical Implications

Primary prevention of obesity is probably more achievable than a cure and has the ability to be more effective, acceptable, cost-efficient and beneficial (Alvarez-Jiménez et al 2008). Obesity prevention should include educating staff and patients alike about the risks of weight gain, more robust monitoring and classification of obesity and mandatory provision of multi-component interventions for lifestyle change, including access to psychological therapies like motivational enhancement therapy. The critical period for health promotion interventions appears to be the first few months of hospital admission and it is suggested that this should be the target of future health promotion interventions.

## Strengths and Limitations of the Study

The prescribing trends and changes to medication were not part of the study objectives; this could have had an impact on our understanding of weight gain at the unit and potentially help in highlighting medications which were more responsible than others in causing weight gain.

Our study did not use subdivisions of BMI as recommended by NICE guidelines (December 2006) which states that people classified as obese should be categorized as obesity I (BMI 30- 34.9), obesity II (BMI 35- 39.9) and obesity III (BMI 40 or more). The risks should then be assessed by comparing their BMI classification against waist circumference. It is also known that BMI may be less accurate in highly muscular people, Asian adults and older people. Other parameters such as waist/hip ratio, measuring skin fold thickness (over the biceps, triceps or below the shoulder etc) could have been a better indicator of excess body fat.

The suggestion of rapid weight gain occurring in the first 12 months is based on a very small subsample (five patients) and as previously discussed, the observation may have been due to multiple confounding factors. We acknowledge that the most significant rise in weight coincided with the introduction of a hospital wide no smoking policy. Furthermore, comparisons drawn on variations in BMI at different sampling times with different study samples may possibly not be generalisable. Hence, future service evaluation efforts at the unit would be focused around individual analysis of the admission ward and long stay ward (acutely disturbed admission ward patients *v* very settled patients in rehabilitation). We also plan to incorporate other parameters of physical health (e.g. baseline bloods) in future studies.

To our knowledge no other study in the UK on weight gain in secure units has incorporated data extending over a period of four years.

This study has highlighted that weight gain is a major problem in our patient group. It has assisted us in reflecting on this matter and initiated a process of change at the unit towards a healthier future.

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**Positive Engagement with Communities through Taiji:
Case Study of a One Day Experiential Workshop**

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# Positive Mental Health – Engagement with Communities through Taiji: Case Study of a One Day Experiential Workshop

Denise Yuen Megson, De Qing Chen, Jackson Chiu

## Abstract

Whilst the physical health benefits of taiji have been reported, there is limited information on the influences of taiji on mental health. This paper reports on a collaborative one day experiential workshop between a university, a local martial arts academy and Mental Health in Higher Education (MHHE). The purpose of the day was to explore the impact of taiji on people's mental health and well-being. The workshop used a multi method approach to explore the potential benefits of taiji. Participants, who were service users and various professionals, were introduced to the philosophies behind taiji and gained an understanding of the concept of qi. This was followed by participants being guided through a practical taiji session to demonstrate how qi can be activated. The remainder of the day was used to deconstruct poetry and narratives to trigger discussions on the range of benefits of taiji. Those participating acknowledged the social benefits of belonging to a community of taiji practitioners. Two pragmatic issues were also highlighted: cultural background being an important influence regarding the understanding and practice of taiji; and that difficulties in gaining access to reputable and qualified teachers can act as a barrier to integrating taiji within educational programmes.

**Key words:** Health and Well-being, Taiji, Benefits to Mental Health, Barriers, Collaboration.

## Introduction

Taiji has a long history as a martial art, dating back some 700 years. Generations of taiji masters have adapted and added to the original movements to help promote the flow of qi (also spelt chi) to internal organs, thus benefiting health.

Chi is a concept fundamental to the understanding and practice of t'ai chi; it is a life-giving energy or `the breath of life' that pervades everything. The Chinese believe that ill health comes from disturbances in the flow of chi which may be blocked, deficient or in excess. (Lewis: 205)

Taiji is widely practised in the Eastern hemisphere as a means of maintaining health. The promotion of qi by sequences of exercise to gather, balance and direct its flow is fundamental to the practice of taiji. Moreover, the mental aspects of focusing on the movements and being aware of the bodily sensations and reactions, has been likened to meditation in motion (Posadzki and Jacques 2009).

In this paper the spelling of taiji is in keeping with the Pin-yin system as opposed to the western spelling of tai chi. The Pin-yin system, introduced by the People's Republic of China, has been in use since 1958 and is an attempt at teaching Chinese pronunciation to foreigners. Pin-yin became an International Standard Organisation (ISO) standard in 1982 and is used exclusively in the media (http://qi-journal.com/culture.asp?-token.SearchID=Mandarin). Another reason for using Pin-yin is to hopefully attract a more global audience to this paper, where search terms using Pin-yin spelling is more common.

## Reviewing the Literature

Available literature on the benefits of taiji has tended to focus on the physical aspects of health with few papers exploring its value in treating common mental health problems such as anxiety and depression (Baron and Foubart 2005; Sandlund and Norlander 2000; Taylor-Piliae et al 2006). However, as a taiji practitioner who has experienced wider benefits, it was felt that an exploration into its potential use for enhancing mental health and well-being was worthwhile.

In 2001, Li et al systematically reviewed 31 original studies identifying the physiological benefits on health from practising taiji. Within the studies reviewed, evidence was available that demonstrated taiji practice can help promote more effective ventilatory responses (Zhuo et al 1984) and that people gained strength and improved their balance (Tse and Bailey 1992; Wolfson et al 1996). Of the 31 studies, only two studies by Jin in 1989 and 1991 appeared to have considered mental well being and the effects taiji has on mood and emotions.

Li et al. (2003) devised a modified form of taiji for use with older adults who were considered frail, and individuals with functional impairment of the muscoskeletal and cardiovascular system. Using a variety of health measures the findings of their research suggested evidence of improvement to both physical and mental health. More recent studies (Brismee et al 2007; Cheung et al 2007) appear to have continued the trend to focus on taiji and its use with older people. Reduction in joint pain, improvement in physical functioning of those with knee osteoarthritis and improvement in balance are all reported benefits (Brismee et al 2007). Likewise, after a 15 week taiji chuan programme, improvement in muscle strength and shoulder joint flexibility in individuals with lower limb disability was reported, even though there was no significant improvement in respiratory and cardiovascular function (Cheung et al 2007).

A more recent systematic review of the literature examined studies that explored the efficacy of taiji on fall reduction (Low et al 2009). This review of seven randomised controlled trials found that taiji had the potential to reduce falls and/or the risk of falls among older people, particularly in those who were relatively younger and not frail.

Qualitative studies have explored the benefits of using taiji to promote health and well-being in pregnant women. Ford-Price (2008) uses autoethnography to articulate how taiji exercises helped her minimise the discomforts during her pregnancy and how the development of stamina and relaxed breathing assisted in her delivery. Similarly, Layhe-Cook (2011), a taiji tutor and a trained National Childbirth Trust antenatal teacher, developed a short course using taiji qigong exercises focusing on the physical, emotional and mental needs of pregnant women.

With regard to mental well-being several studies have shown positive results in the use of taiji as an intervention. Taylor-Piliae et al (2006) examined changes in psychosocial status following a 12-week taiji exercise intervention conducted among immigrant Chinese people living in the USA, who were at risk of cardiovascular disease. The aim of the study was to determine if taiji exercise improves affect and mood, and reduces stress. The twelve week programme reported a statistically significant reduction in perceived stress, improvement in mood and an increase in perceived social support. However, a longer time period was needed to assess whether taiji could be performed with confidence. Limitations of the study included issues relating to participants' understanding of the measurement tools and their level of education. Such limitations led the authors to question whether or not the benefits were solely down to the taiji activity or if they had been influenced by the location; that is attending a local community centre and participants having easy access to other health care services (Taylor-Piliae et al 2006).

Sandlund and Norlander (2000) reviewed all studies directly concerned with taiji in connection with stress and well-being as reported in the Psychlit and Medline databases during 1996–1999. The authors concluded that taiji had a role to play in the reduction of stress due to its relaxation and meditative effects, but were unsure whether this effect could be in part due to participants doing something that they enjoyed. Caldwell et al (2009) compared the effects of Pilates and taiji on self-efficacy, sleep quality, mood and physical performance of college students. The Pilates group scored better for both self-efficacy and mood, but the students using taiji also showed an improvement in both these areas. A case study on the role of taiji in reducing anxiety and enhancing the mood of children with special needs concluded that taiji had the greater impact on the child who was hyperactive and had heightened anxiety (Baron & Faubert 2005). However, the authors were conscious of external factors which could have impacted on the results. For some of the children the issue of having a history of 'inherent failure' may have led to their trying to master the physical movement as opposed to paying attention to the breathing and centering that leads to a sense of well-being.

As well as exploring the benefits of taiji on those who might use health and social care services, another study evaluated the effectiveness of a self care programme for nurses (Raingruber and Robinson 2007). The nurses were managing complex cases, working in very stressful environments and had a high turnover of staff. Three different classes of yoga, taiji and meditation or reiki were offered to nurses who were asked to keep a journal and reflect on a series of questions. The participants of taiji classes reported feelings of warmth or tingling sensations and perceived that their ability to problem solve and focus on patients needs had improved. The ability to notice physical sensations and relate to them indicates that individuals could disassociate themselves from external stressors and experience a period of calmness and relaxation. It was also felt that the calmness they experienced provided them with the ability to better pick up on cues from patients. The nurses participating in the study also reported having a more positive view of their work (Raingruber and Robinson 2007).

It would appear from the literature that whilst the effects of taiji have been well researched in terms of physical health problems, there is growing evidence about how it might be used as a way of maintaining mental health and well-being, linked to exercise and the cultivation of mindfulness. In order to achieve these goals, it is necessary to attend to the subjective experience of those who have engaged in taiji and ensure that they are offered the opportunity to explicate their experience.

**The One Day Collaborative Workshop**

An opportunity arose to apply for funding from Mental Health in Higher Education (MHHE) to facilitate a workshop promoting mental health in Higher Education Institutions.

Collaboration was sought from a local martial arts academy to facilitate a workshop that was open to Higher Education staff, users of mental health services and staff in practice settings. Ethical approval was sought and granted from the School who hosted the event and a contract was signed by the Head of School, who agreed to MHHE terms for hosting the event. The publicity material advertising the day made it evident that there was an experiential element to the day and all publicity material was seen and agreed with a facilitator from MHHE. The aims and outcomes for the day were clearly identified and participants had to register to attend the day. The workshop aimed to introduce tai chi movements as a way to manage and reduce stress and to enable participants to meet and network. The main outcomes were to develop knowledge of the philosophy of taiji and to have a basic understanding of taiji movements and their potential benefits. MHHE also required a report and evaluation of the day's events and one of their advisors attended the workshop.

The workshop was organised and advertised nationally by MHHE and local networks. There was a limit on the numbers of places available and 20 participants enrolled for the workshop. Four participants did not attend on the day due to sickness and problems with travel.

## The Participants

A total of 16 people attended the advertised workshop, six of whom were carers and two were professionals who were using taiji in their services. The other eight participants were: one person receiving services from a mental health service; two lecturers; three student support staff from other universities in the United Kingdom; a mental health community worker and a social work student who was on placement with her; and a representative from MHHE. Not all participants were taiji practitioners and at least three had never attempted taiji at all. There were seven men and nine women participants, with ages ranging from mid twenties to mid sixties. Five of the participants were Chinese and the others were white British. Their main reasons for participating were to share their experiences and to gain more knowledge of the subject area. In particular the lecturers were keen to see whether taiji could be included in their module on stress management whilst the student support personnel were keen to explore the possibility of introducing taiji to students in their own Higher Education institutions.

## The Structure of the Workshop

A short presentation on the global strategy for preventing deaths from treatable causes (World Health Organisation 2002) and the national cross-government plan to promote physical activity (Department of Health 2005) was used to set the workshop in context. This was followed by a discussion on the philosophy of taiji. After completing the more theoretical aspects of the day, the participants were asked to engage in a short exercise to experience the feeling of 'qi' as this provided a basis for the experiential element of the workshop. The importance of qi was then explained to the participants.

The experiential element of the day was facilitated by an experienced Taiji Master and his senior student. It was important to engage credible teachers in order to provide authenticity to the experience. As the majority of participants had not previously experienced taiji, it was important that their experience was such that they were able to make sense of it in relation to their pre-conceived thoughts. The benefits of being able to gain data related to cognitive abstract concepts from concrete experience is well documented (Rainey and Kolb 1995). Active experimentation and reflective observation transforms learning, which often become guides for new experiences. The practical elements started with a series of warm up exercises followed by breathing exercise. Some basic postures for relaxation, which can be extended to train and improve concentration and visualisation, were introduced. The group proceeded to try out exercises to gather and direct 'qi'. Participants were first shown the actions followed by an explanation as to how to perform them. Analogies were used to help participants relate to the actions and to aid visualisation. For example one action of 'testing energy' is likened to standing in a warm sea and feeling you are pushing and pulling back against the water. There should be a sense of resistance in the movements and breathing follows the pull/push rhythm. The experiential work concluded with a demonstration of a 'form' which is a collection of postures with linking steps to create a sequence. The function of these movements is to improve balance, timing and sensitivity, plus the regulation of breathing (Everyday Tai Chi).

In the afternoon, narratives and poetry were used to explicate some of mental health benefits experienced by taiji practitioners. Poetry has been used in the analysis of lived experiences to provide insights into various experiences of mental illness, for example depression (Gallardo et al 2009), whereas Lyle (2009) used narrative as a way of understanding self.

The narration offered to the group was from a taiji practitioner who competes at international level. His story provided his perspective on the psychological benefits of taiji, related to his achievements and self-esteem. By contrast another practitioner used a poem to illustrate the bodily sensations and the pure joy the sequence of movements generates for her. Even though she does not compete in competitions there was a similar sense of personal achievement in mastering the movements. For this person there was also the sense of being on a journey and being creative.

Participants were then divided into two smaller groups and discussions were then used to explore participants' experiences and thoughts on the potential and actual benefits of the experiential taiji exercises that they had taken part in. The discussions focused on what promotes mental health and a sense of well being and how taiji might contribute to this state of wellbeing. Each of the groups had a facilitator who made notes on flip charts. At the end of the small group discussions, a plenary session was used to draw together all the views and opinions. The content from the flip charts was transcribed onto a themed list which included how physical activity can be promoted in educational and service settings and how to take forward ideas from the day. This list was sent out to the participants after the event for verification and further comments but there were no further additions from the participants. The day was then evaluated using a structured questionnaire.

## Feedback from Group Discussion at the Workshop

Benefits identified by participants who practice taiji included improvements in physical health such as being able to sleep better, improved immunity to common ailments, improved balance and improved mobility. It was suggested that good self-esteem would be achieved through the ability to master a form or sequence. A few participants talked about being part of a network of local people, of their role as volunteers visiting schools in their area to demonstrate taiji, and globally as a community of taiji practitioners:

> We visit our local schools to teach the school children, to show them taiji
> Participant A.

Some reported feeling positive, happy after engaging in taiji exercise, and for one carer, taiji provided her with the motivation to carry on with the care of her husband who has dementia:

> It is hard work. My husband has dementia. Doing taiji keeps me strong
> mentally to continue. Participant B

The individual who used mental health services shared with us that he likes attending taiji classes as it helps him to relax and feel calm. Even participants who have never practised taiji felt the essence of 'qi' during the experiential session:

> Feels like something between the palms…cannot easily push palms
> together. Participant C

The themes emerging within the group discussions echo those in the published literature: improved sleep (Caldwell et al 2009); improved mobility and balance (Li et al 2001); and elements of positive well being and creativity explicated through the poem which illustrated the joy of the sensations and movements whilst performing taiji (Sandland and Norlander 2000; Raingruber and Robinson 2007). A sense of calmness and relaxation is in keeping with the findings of Taylor – Piliae et al (2006), Raingruber and Robinson (2007) and Baron and Faubert (2005).

The participants at the workshop identified additional benefits to mental health. Some reported a sense of self achievement and increased self-esteem from mastering a 'form',

teaching others or from competing at international level. One participant reported using taiji to help her maintain motivation in a demanding caring role whilst health professionals at the workshop reported using taiji to facilitate recovery in users of mental health services. Participants who have attended classes/groups reported a sense of belonging and support from the immediate group whilst some acknowledged the presence of a community of taiji practitioners. The participants were keen to network and agreed that their contact details could be shared.

Some of the barriers to the use of taiji as a way to promote positive mental health were identified as: access to reputable teachers; the influence of culture on choice of taiji as a form of intervention; and the length of time it takes to master the basics and thus the delay before benefits are realised. There are ways to verify the authenticity and reputation of taiji teachers through the Taiji Union for Great Britain, but the relationship between teacher and student and the teaching style can influence the enjoyment of the art. In light of this, choice of teacher is an important consideration when starting to use taiji. As for the influence of culture, with greater exposure to taiji and better understanding of its benefits, taiji is seen less as a mysterious eastern activity. The presence of the internet has helped by making literature on taiji more accessible and publicising taiji events from all over the world including those taking place in the Western hemisphere. Nevertheless, there is a long way to go before taiji becomes part of mainstream heath care interventions in Western society. In part this might be related to the philosophies rooted in taiji and these being more in keeping with Chinese culture and their belief system. Taiji exercises are 'considerably different from the "no pain, no gain" mentality of western exercise' (Yang 2008: 9) as the gentle energy gathering/nurturing exercises can be easily practised daily. However, it does take time and effort to learn the different basic movements and to co-ordinate the breathing with the movements. Yang et al (2007) reported it took participants four months to memorise a seven movement choreographed taiji form. Regular practice is preferable to long irregular sessions, so beginners need the support of teachers to access appropriate resources to help them perform the basic exercises regularly.

## Future Research Opportunities

The workshop participants were keen to engage in qualitative research to explore the topic further and this is a potential opportunity for community engagement for the School. The collaboration provided further understanding of inter-professional education by engaging with taiji experts, practitioners and health professionals who were using taiji as an approach to promoting positive mental health. It brought into focus aspects of working collaboratively (Lowndes and Skelcher 1998) in a multi-agency context by confirming that personal factors and working relationships between partners were of prime importance.

## Conclusion

Whilst a number of studies exploring the use of taiji on physical and mental well-being are quantitative in nature, the strength of the work reported in this paper lies in it being qualitative, and thus able to highlight some rich personal experiences of using taiji. The feedback from the workshop does in fact re-iterate some of the findings from other published studies, thus adding to a growing body of knowledge. In addition participants were able to identify possible barriers to accessing taiji and/or including it in an educational curriculum. It has been decided to adapt the workshop into a session on the 'Promoting Positive Mental health' module which forms part of the nursing curriculum for second year mental health student nurses. Perhaps this is a good starting point in teaching neophyte nurses a different cultural intervention that they can practise, master and hopefully use to improve their own mental well-being and the mental well-being of those in their care.

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**Examining the Literature on the Efficacy of Equine Assisted Therapy for People with Mental Health and Behavioural Disorders**

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# Examining the Literature on the Efficacy of Equine Assisted Therapy for People with Mental Health and Behavioural Disorders

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## Abstract

This review aims to explore the literature relating to the efficacy of Equine Assisted Therapy (EAT) during which horses are used as a tool for emotional growth and learning helping adults and children with mental health and behavioural problems, such as mood disorders, addictive behaviours and communication difficulties. EAT arose during the 1970s, when alternatives to traditional talking therapies were created. A search for relevant literature was undertaken, using electronic and manual search strategies. The data bases used included, CINAHL, MEDLINE, AMED and INTERSCIENCE. It was evident that there was limited research-based literature within the UK compared with the USA. However, magazine articles, reporting opinions and case studies, originating from Canada and Northern Europe, were found useful and informative. The literature revealed promising results in the use of EAT in increasing positive and reducing negative behaviours as well as in proving beneficial for those suffering from general mental health problems. The review also indicates the need for further research and discusses its implication for practice.

**Key words**: Equine Assisted Therapy; Efficacy; Mental Health problems; horses; psychotherapy; children and adults.

## Introduction

This paper explores the literature related to the efficacy of Equine Assisted Therapy (EAT) for people with mental and behavioural disorders, across the lifespan. The Equine Assisted Growth and Learning Association (EAGALA 2007) notes that EAT arose during the 1970s, when alternatives to traditional talking therapies were created. It is designed to provide a short-term, intensive treatment programme. Sessions usually last between 60 to 90 minutes and require setting up activities involving horses, which are facilitated by a therapist and horse practitioner. These activities require the client or group to convey certain skills, for instance, verbal communication, assertiveness, creative thinking and problem-solving, leadership, taking responsibility and teamwork. Taylor (2001) explains that EAT involves the use of horses in the treatment of psychological problems and that therapists can integrate equine based activities to complement other approaches, such as cognitive behavioural therapy and psychotherapy.

An increasing body of evidence shows that people suffering mental health problems, who struggle with more orthodox talking treatments, can be helped by non-verbal interaction with horses. Tidmarsh (2005) contends that the relationship between horse and client assists in developing insight and understanding of themselves, awareness of their difficulties and they can subsequently become challenged to change. Due to a small number of EAT professionals in the UK and Northern Europe (approximately 100) in contrast with the 3-4,000 in the USA (Tidmarsh 2005), it appears a less accessible form of therapy here. Currently in the UK, there are a handful of private clinics, such as the Priory's North London Clinic, Castle Craig Hospital and LEAP (Leading Equine Assisted Psychotherapy) which offer EAT. So far, it has proved difficult to persuade the NHS to recognise the benefits of using EAT. Tyler (1994) points out that EAT can be expensive and time consuming. However, Mann and Williams (2002) dispute this argument. They found more progress in a shorter time and at less cost in some cases of conduct disorders, mood disorders and psychiatric disorders. Powell (2008) suggests that provisions for EAT should be made for those who

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have not been reached through other conventional methods and who cannot afford to seek private care.

Like other developing fields, EAT currently attracts more literature on practice than on research and theory. However, there are a number of research studies within the UK currently awaiting publication (Bexson 2008). Qualitative research results on EAT are proving promising. Quantitative studies have been less successful due to methodological issues. This may change once new methods are used to measure the benefits and the controls of other contributing factors. Overall, the research findings have been inconsistent and closer scrutiny of the literature is necessary.

## Searching for Relevant Literature

Resources used to retrieve relevant literature were accessed through electronic and manual strategies. Single and combined keywords used to conduct the search were: 'Horses', 'equine', 'therapy', 'psychotherapy', 'animals', 'horse riding', 'treatment', 'mental health'. The combination of search terms was designed to filter out literature on the use of horses for physical treatment such as hippotherapy, as due to word limitations this review will focus on the psychological benefits. Table 1 gives a breakdown of the search findings.

## Table 1 Literature Search Findings

| Key words used [single & combined] | Databases & Websites | No. of Citations found | Type of literature |
|---|---|---|---|
| Horses Equine Therapy | CINAHL | 9 2 | Reviews Studies |
| Psychotherapy | MEDLINE | 15 2 | Reviews Studies |
| Animals | AMED | 2 | Reviews |
| Experimental therapy | INTERSCIENCE | 1 | Study |
| Horse Riding | www.eagala.org/research.htm | 5 | Studies |
| | www.psychosocial.com | 1 | Review |
| Treatment | www.therapytoday.net | 1 | Discussion paper |
| Mental Health | www.taoofequus.com | 1 | General information |

A Google internet search was also performed using the above keywords which revealed various information and articles. Caution was used here, as information from such sites did not always prove reliable and evidence-based and was, at times, anecdotal so rejected. Books and magazines were included in the search strategy. The search was extended beyond the UK to embrace an international perspective as not a single published study was found from within the UK. This is a relatively new field in the UK but countries such as the USA and Canada have been conducting research in EAT for over a decade. Overseas literature was considered appropriate for the purpose of this review as associations, such as EAGALA, operate worldwide providing professional standards and guidelines for practice. (See Table 2).

| Table 2. Summary of studies within this review | | | | |
|---|---|---|---|---|
| Author, Year & Setting | Design | Area of focus Methods (Sampling, data collection & analysis) | Key Findings/results | Limitations |
| Klontz et al (2007) Residential programme in USA | Open clinical trial | Finding out whether Equine Assisted Therapy (EAT) would reduce psychological distress & enhance psychological well-being. Non-randomised sample: 66 individuals 8 programmes (only 31 participants included in the data analysis due to missing data i.e. 9 men 22 women. Age range 23-70yrs: 90% Caucasian from 13 states. 28 hrs of EAT in a group therapy: 8 participants per group. Pre-test, post-test 6 month follow up test. Multiple analysis of variance with repeated measures on the brief symptom inventory global severity index & Personal Orientation Inventory | Significant stable reductions in overall psychological distress enhancements in psychological well being from pre-test, post-test follow-up. Fewer psychological symptoms reductions in intensity of distress. Reported feeling more orientated in present, better able to live in the here & now, less burdened by regrets, guilt resentments, less focussed in fears, more independent self supportive | Non-randomised sample. Difficult to know whether changes were as a result of treatment, time alone or other factors unrelated to treatment. Client self report / subjective data can be unreliable. Greater improvement in functioning could be due to clients wish to portray this rather than the truth. No data collected on individuals who declined to participate in the study. Incompletion of 6-month follow-up data from some of the participants meant differences between stability of change in the group who responded 6 months following treatment & the group who did not respond. |
| Leslie A. Russell-Martin (2006) North Central region USA | comparative quantitative design | Comparing equine facilitated couple therapy (EFT) with solution focused couple therapy (SFT). 10 couples received 6 EFT sessions & 10 couples 6 SFT (n=20 heterosexual couples i.e. 40 individuals); aged 21-45yrs Relationship status: committed; faithful; monogamous; married; living together; pre-marital separated or exclusively dating. Dynamic Adjustment Scale (Spanier 1967) pre-therapy, week 1, 3 & 6. Data collection: relational experience, relationship length, horse experience, therapy experience, age, income, years of education. Multivariate analysis of variance (MANOVA). | Both EFT & SFT groups were similar in descriptive variable responses. The EFT group showed a significantly higher degree of marital satisfaction & relational adjustment than the SFT group by the 6th week of treatment, demonstrated by scores on the DAS. Initially no difference in the scores on week 1& 3. Gender effects did not exist between or within test groups. | A number of different, pre-defined types of relationship studied, based on the researcher's opinion. Potential for unconscious researcher bias: Therapist in this study was also the researcher Lack of a control group & pilot study. |
| Schultz et al (2006) New Mexico | Pilot study | Unselective Consecutive Sampling: 63 Children (37 males & 26 females) 4yrs – 16 yrs old. 51% non-Hispanic white, 46% Hispanic white & 3% black. 40% (n=25) history of inter-parental violence at home; 27% (n=17) abuse &/or neglect; 20% (n=12) sexual abuse; 32% (n=20) at least 1 parent with history of substance abuse; 57% (n=36) mood disturbance diagnosis; 16% (n=10) ADHD; 8% (n=5) PTSD; 5% (n=3) disruptive disorder & 5% (n=3) other disorders. DSM-IV used for classification of mental health diagnosis. 100-point rating scale Global Assessment Functioning (GAF) measuring psychological, social & school functioning for 6-17yrs. | All children showed an improvement in GAF scores. Young children showed the greatest improvement & children with a history of intra-family violence & substance abuse tended to show a greater improvement. A statistically significant correlation between the % improvement in the GAF scores & the number of treatments given. Children with history of physical abuse & neglect had a statistically significant greater % in GAF improvement score after treatment then those who did not have a history of abuse or neglect No statistically significant difference in scores or % improvement between Hispanic & Non-Hispanic | Couples not seeking therapy are not sampled in this study. Hence, increased relational adjustment not measured on a normative sample baseline. The sample was self-selected so may be considered bias The Global assessment scale is the only outcome measure of the study it limits results/findings. It is possible other variables effected the pre & post treatment studies & increase GAF scores It is unclear how age, gender & environment effects the results The 14 children that dropped out were excluded from further analysis |

| Continued: Table 2. Summary of studies within this review | | | | |
|---|---|---|---|---|
| Author, Year & Setting | Design | Area of focus Methods (Sampling data collection & analysis) | Key Findings/results | Limitations |
| Trotter et al (2008) South Western region, USA | Comparative quantitative study | Comparing Equine assisted counselling (EAC) with classroom-based counselling. n=205 students volunteered, 41 dropped out. 164 completed the study:102 male 62 female children at risk of academic & social failure due to behavioural issues, learning difficulties, or social adjustment concerns 136 Caucasian, 12 African-American, 11 Hispanic & 5 other ethnicities in grades 3-8. Behavioural Assessment System for children (BASC), self rating scale (SRS) & parent-rating scale (PRS). PRS sent home for the parents to complete pre & post treatment. SRS completed by students prior 1st & at end of final treatment sessions Psychosocial Session Form (PSF) –6 point likert scale, used to rate client social behaviours at the end of every treatment session. ANOVA used to compare the differences between the EAC & RD groups. | Participants in the EAC group demonstrated a statistically significant decrease in 5 negative behaviours & an increase of 2 positive behaviours. The SRS indicated this. The PRS indicated statistically significant improvement in 12 areas. Participants in the RD group demonstrated a statistically significant decrease in 1 negative behaviour & an increase in 4 positive behaviours. EAC proved to be effective with at risk children & adolescents + EAC treatment determined to be superior to RD treatment. | *The data collection methods limit full details of experience/improvement Client self-report data can be unreliable eg subjective view & a greater improvement in functioning could be due to clients wish to portray this rather than the truth, hence participant bias. The Psychosocial form has not standardised on a large national sample. Unclear if representative to the general population & varying age populations, hence further research is needed to established its validity & reliability |
| Shultz (2005) Residential basic care facility, USA | Experimental Design | Effects of EAT on the psychosocial functioning of at risk Adolescents Convenience sample. Adolescents aged between12-18. n=15 in treatment group (8 males & 7 females; 5 in individual EAT & 10 in group). N=14 in control group (9 males & 5 females). Two types of youth within each group: those who lived in residential basic care facility & those who did not Different backgrounds included: living below poverty line; victims of crime & violence; abuse or neglect; alcoholic or drug abuser parents; divorced, separated or never married parents; more than 4 siblings living at home. Some of the behaviours/issues include anxiety, depression, fearfulness, hopelessness, self-harm, paranoia, OCD, hallucinations, delusions, suicide, mania, & eating disorder. Data collection: 6, 8, or 10 weeks of individual or group therapy. Youth outcome questionnaire (Y-OQ): A parent-reported measure of wide range of troublesome behaviours & moods, which commonly apply to adolescents. It assesses the occurrence of observed behaviour change. Whereas the Youth Outcome Questionnaire (Y-OQ-SR) measures the same criteria but is completed by the adolescent. They both assess the psychological, symptomatic, & social functioning of adolescents. | Both child & parent reported that adolescents who received EAT experienced greater total therapeutic change in psychosocial functioning & improvement in intrapersonal distress than those who did not. Improvement in intrapersonal relations also noted by both child & parent noted. However, only the child noted improvement in somatic pain whereas only parents noted improvement in social problems such as, running away, truancy, sexual problems, destruction of property; Behavioural Dysfunction & critical items change. | Data were analysed from those participating in either group or individual EAT but no distinction was drawn between the 2 treatment modalities. The sample size was not large enough to compare the effects of EAT between race, gender, age & risk level. The study does not address which aspects of EAT are most responsible for the therapeutic benefits. The researcher & other therapists collecting data were aware of which participants were members of the control group or the experimental group. |

## The Effects of Equine Assisted Therapy on Behaviours

There is an increasing amount of discussion on the effects of EAT on behaviours in both children and adults. According to the EAGALA (2007), this therapy boosts skills such as non-verbal communication, assertiveness, creative thinking, problem solving, leadership and teamwork. Thomas (2002) was able to report that a group of 17-year-old boys in a correctional programme, who required physical management by staff on a daily basis, learned how to control their violent outbursts when EAT was introduced to their programme. According to Mann and Williams (2002), 82 per cent of youths participating in EAT showed significant clinical improvement after five sessions. They were also reported by their parents to have previously failed to make any progress during conventional methods of therapy. Bates (2002) asserts that he reviewed three 1997 studies in which horses were successfully used in decreasing the number of acts of aggression in young people who were seriously emotionally disturbed. Gamache (2004) reviewed literature on a randomised control trial by Mackinnon et al (1995) where therapeutic horseback riding helped improve attention span, social interaction and confidence amongst 19 children. Moreover, besides having a calming effect on behaviours, Karol (2007) describes how a 15-year-old old girl, who had no energy and spent most of her day in bed through no physical cause, became energised during her EAT sessions. This energy gradually converted to other environments.

Klontz et al (2007) conducted an open clinical trial on the effectiveness of EAT. This trial was to establish whether EAT would reduce psychological distress and enhance psychological well-being. A non-random sample of 31 individuals (9 men 22 women) participated in a 4½ residential equine assisted experimental programme in the Southern United States. They were aged between 23-70 years old. 90 per cent were Caucasian and from 13 states in the USA. The Brief Symptom Inventory (BSI) (Derogatis, 1993) and the Personal Orientation Inventory (POI) (Shostrom 1974) were administered prior to treatment, immediately following treatment and six months after treatment. The results of the clinical trial indicated that participants showed significant and stable reductions in overall psychological distress and enhancements in psychological well-being from pre- and post-test and follow-up.

## EAT Compared with more Established Therapies

Tyler (1994) believes that work with horses lowers defensive systems, challenges old behaviours, develops insight and perspectives for dealing with problems in a way that conventional 'office' therapy does not. Ratey (2001) argues that for youngsters, in particular, talking therapies can be unsuccessful because they find it hard to cognitively articulate their emotions and that drug therapy for young people can be unrewarding because their bodies are sensitive to medication. In addition, Karol (2007) and MacDonald (2004) point to difficulty in encouraging young people to make a conscious free decision whether to start a therapy or not. They believe some children, especially those who had negative parental interactions, can often view therapists, teachers or adults in general with mistrust or apprehension. However, the fact that this therapy often starts in an environment away from traditional settings, can be a strong motivator.

Karol (2007) points out that there are few EAT programs that utilise the expertise of masters or doctoral-level psychologists, clinical social workers, or psychiatrists. She asserts that often people working in these programmes know more about horses rather than the theory and practice of psychotherapy. She believes that when an advanced level clinician works with EAT, the therapeutic work can move from narrow uses of cognitive behavioural techniques and here-and-now therapies, and limited stages of personality development to a more complete psychotherapeutic experience and involvement.

A comparative study conducted in the USA by Trotter et al (2008) compared the efficacy of EAT with classroom-based therapy. A convenience sample of 205 mixed gender students, at risk of academic and social failure as a result of behavioural issues, learning difficulties or social adjustment problems, was selected. The students were from different ethnic groups from the South Western region of the USA. Data were collected through the Behavioural Assessment System for Children, Self Rating Scale (SRS) and Parent Rating Scale (PRS) (Reynolds and Kamphaus 1992) and a Psychosocial Session Form, 6 Point Likert Scale (PSF). The PRS was sent home for the parents to complete pre- and post-treatment. The SRS was completed by the students before the first and at the end of the final treatment sessions. The PSF was used to rate the students' social behaviours at the end of every treatment session. The study showed a statistically significant decrease in five negative behaviours within the group receiving EAT, compared with one negative behaviour decrease in the classroom based therapy group. However, despite the benefits of a repeated measure design which helped determine how much change occurred between treatment 1 and 12, also during each session, the reliability of self report repeated measures could be questioned with the familiarity of completing re-administered questionnaires and the risk of participant bias when using self-rating scales ( Houghton & Ousley 2004; Polit Hungler 2008).

Russell-Martin (2006) conducted a comparative study in the USA between, EAT and Solution Focused Therapy (SFT) for couples. Half of the participating dyads (n=40) received six sessions of EAT and the other half six sessions of SFT. The couples were heterosexual and aged between 21 and 45 years old. Couples in this study were married, living together, pre-marital or exclusively dating. A Dynamic Adjustment Scale (DAS) developed by Spanier (1967) was issued prior to therapy then on weeks 1, 3 and 6. There was, initially, no difference in the scores on week 1 and 3. However, the DAS scores showed that the EAT group had a significantly higher degree of marital satisfaction and relational adjustment than the SFT group by week 6 of treatment. The researcher who was the only therapist could have had the potential for unconscious researcher bias (Lawrie et al 2000), which may have influenced the study outcome. For instance, the many different relationship statuses in this study seem to be based on the researcher's subjective view.

## Mental Disorders and Equine Assisted Therapy

There are a number of discussions concerning the efficacy of EAT for the treatment of mental disorders. Lancia (2008) suggests that EAT is helping treat psychologically injured combat veterans. Some of the psychological injuries included post traumatic stress disorder, depression, grief, panic attacks and sleep disorders. He describes how the horse unlocks fear, stimulates powerful thoughts and feelings, and gives individuals a sense of acceptance by the community as well as shifting feelings of detachment and numbing. However, it is unclear whether the soldiers had tried other methods of therapy or how many have benefitted from EAT therapy so far.

Powell (2008) contends that EAT is very effective for people with eating disorders and refers to such patients as being very particular about which horse they work with and not wanting to choose one which they perceive as having a defect. The patient's initial reaction is avoiding the horse even if it is desperate for attention. Such a reactive behaviour opens doors to physical appearance issues and body image perceptions. Lavender (2006) describes EAT as reducing fear in eating disorder patients teaching them to let go of control. He also contends that EAT successfully helps treat addiction patients and personality disorders and assists in resolving recent or old trauma.

In New Mexico, Schultz et al (2006) conducted a pilot study to test the efficacy of EAT on a sample of 63 children (37 males and 26 females) aged between 4 and 16 years old. 40 per

cent (n = 25) experienced inter-parental violence at home, 27% (n = 17) had a history of abuse and/or neglect, 20 per cent (n = 12) had history of sexual abuse and 32% (n = 20) had at least one parent with history of substance abuse. 57% (n = 36) of the children had mood disturbance diagnoses and disruptive disorders. The ICD-10 (1994) was used for classification of diagnoses. The mean number of EAT sessions received was 19. The Global Assessment Functioning (GAF) 100 point rating scale was used to assess treatment, measuring psychological, social and school functioning for children. The study indicated that all children showed an improvement in GAF scores. Young children, children with a history of intra-family violence and substance abuse showed the greatest improvement.

Shultz (2005) examined the effects of EAT on the psychosocial functioning of at risk adolescents. A convenience, mixed gender sample of 29 adolescents, aged between 12 and 18, was divided into two groups, 15 received EAT and 14 did not. The adolescents came from varied socio-economic backgrounds displaying a wide range of mental or behavioural problems, such as depression, anxiety, hopelessness, self-harm, paranoia, obsession, hallucinations, delusions, mania and eating disorders. The Burlingame et al (1996) Youth Outcome Questionnaire (Y-OQ) was used to collect data from parents and the (Y-OQ SR) from the adolescents. Both tools measure the psychological, symptomatic and social functioning of the adolescent. The study revealed that the adolescents who received EAT experienced greater total therapeutic change in psychosocial functioning than those not exposed to EAT. Both adolescents and caregivers reported statistically significant changes in symptoms of depression, anxiety and self-harm but only the caregivers reported significant change in other symptoms. However, no clear distinction was made between those who received individual EAT and group EAT. These two treatment modalities may have retrieved very different results. Group therapy and individual therapy have many differences, for example, within group therapy, trusting others and confidentiality may limit sharing or disclosure (Parsons 2004).

## Implications for Practice

In this literature EAT is portrayed as a powerful and effective approach to help treat people with a variety of mental and behavioural disorders. However, due to the small number of studies, it is impossible to identify whether one therapy approach used within the EAT model is superior to another. Most of the studies consisted of adolescents and all were conducted in the USA. It is also difficult to establish if EAT is effective for all mental health disorders due to lack of studies on each specific disorder and to determine whether EAT alone was responsible for improvements. In the past, other experimental therapies such as art therapy, drama therapy and music therapy were treated with suspicion as a treatment modality for people with mental health problems. Now, they are all offered on the NHS. It is becoming more accepted that healthcare professionals have different ways of relating to and caring for their patients. Therefore, exploring a different therapy could only complement and enhance the care the NHS delivers as well as other care organisations.

## Conclusion

This review suggests that EAT is a form of experimental therapy that enhances positive behaviours, reduces negative behaviours and has helped people with mental health problems. The studies have also indicated that EAT can be as effective as other therapies currently used. Thus, the potential of EAT, as an alternative to talking and existing experimental and creative therapies, is recognised. While the reviewed literature is fascinating and has revealed positive results in EAT on mental health and behavioural problems, research studies that are more comprehensive are required, especially in the UK before claims could be made for its evidence-based value. Empirical studies, such as

biofeedback tests to measure heart rate variability, skin conductance level and brain wave activity and blood samples measuring neurotransmitter uptake could significantly enhance research outcomes (Lentini and Knox 2008). Ways of measuring the benefits and controlling other contributory factors could also be refined for future research to help, for example, identify whether the changed environment alone would provide the same results as Trotter et al (2008) have suggested (Bexson 2008). Furthermore, research studies such as randomised controlled trials in service users with reasonably homogeneous conditions and with the assessors of outcome blinded to the treatment condition, as well as an analysis of cost against benefits, should be encouraged to attract NHS interest. Provision of EAT on the NHS would increase the number of equine therapists helping EAT to become more accessible in the UK as it is in other parts of the world.

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# Young People with Learning Disabilities and the Development of Sexual Relationships

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## Abstract

In modern society the needs of young people with learning disabilities to develop sexual relationships is increasingly recognised, and supported in legislation and social policy. The aim of this small scale, exploratory study was to understand whether young people with learning disabilities receive sex education and are given accessible information and support relating to sexualised behaviours.

The study gained professional and parental views on this topic, together with those of the young people to understand their future aspirations and the barriers they may face. The research design involved semi-structured interviews with 12 purposively selected respondents including teachers, public health nurses, young people and their parents.

Results indicated that this group of young people do receive sex education but that misunderstandings about sex and relationships are still prevalent. Professionals and parents may lack the knowledge and confidence to provide appropriate information in an accessible manner, and for professionals the emphasis is on managing inappropriate sexualised behaviours. When it comes to preparing young people for emotional relationships all those involved in the study struggled with this and the young people's aspirations differed from those of their care givers. The study concludes that support in this particular area of personal development needs to be developed.

**Key words:** Young People, Learning Disabilities, Sex Education, Sexual Development, Relationships.

## Introduction

Historically people with learning disabilities have been discriminated against in terms of sex and relationships. Traditional misconceptions have fallen into two categories; either that people with learning disabilities exist in a perpetual childhood and are therefore not sexual, even when physically mature (Fairbairn et al 1995); or that they demonstrate inappropriate sexual urges that need to be controlled to prevent risks to self and others (Neufeld et al 2002).

Whilst such beliefs may still pervade societal attitudes towards people with learning disabilities, there has been a growth in recent years in research concerned with young people with learning disabilities developing and engaging in sexual relationships. This has been fuelled largely by changes in legislation and social policy that emphasise the human rights of disabled young people (Hall & Hill 1996). People with developmental disabilities have the same emotional requirements for love, affection and fulfilling interpersonal relationships as does any other person (Guilio 2003). Article 8 of the Human Rights Act (1998) states that every human being has the right to respect for private and family life, and a recent Department of Health (DH) booklet states that this article is relevant to the rights of those with learning disabilities in relation to issues such as independent living and personal and sexual relationships (Department of Health 2010). The Mental Capacity Act (2005) states that a person must be assumed to have capacity to make decisions unless it is established otherwise. This supports the rights of people with learning disabilities to make independent, informed decisions in respect of relationships and sexual behaviour.

The Education Act (1996) requires all schools to have a sex and relationship education policy and states that children with special educational needs and learning disabilities in mainstream and special schools must be properly included in sex and relationship education (Department for Education and Employment, 2000 para 1.26).

In 2001 Valuing People set out the government's commitment to improving the life chances of people with learning disabilities, emphasising their legal and civil rights to a decent education, to marry and have a family (Department of Health, 2001, para 2.2). The policy goes on to emphasise that it is important for people with learning disabilities to receive accessible sex education and information about relationships and contraception (Department of Health 2001 para 7.39).

In accordance with the shift in policy and legislation Healy et al (2009) report that most people with learning disabilities aspire to relationships, marriage and children. However, there is some evidence in the academic literature that such young people do not gain information regarding sexuality and development from their peers in the same way as their non-learning disabled contemporaries. It is suggested that this may be due to their lower levels of social skills and limited opportunities to socialise independently which impacts negatively on the formation of close emotional relationships (Garbutt 2008).

In the light of the above, the aim of this small-scale, exploratory study was to investigate if in one particular setting young people with learning disabilities are receiving support and sex education to allow them to develop relationships. The study compared professional and parental views on this topic with those of the young people in order to gain a fuller understanding of the issues from a range of perspectives. By involving young people directly in the study it was intended to raise their awareness of the importance of sex education, and inform those involved in their welfare of issues that may previously have been considered a taboo subject.

## Literature Review

A review of the academic and grey literature was undertaken to source relevant material. Search terms included:

- learning/intellectual disabilities and sexuality
- learning/intellectual disabilities and sex education
- sexual behaviour and learning disabilities and
- learning disabilities and parent/carer perspectives.

A preliminary search using the Web of Knowledge allowed access to a range of data bases. This was followed up by specific searches of the reference lists of relevant papers, in particular papers in the Journal of Intellectual Disability Research. Policy documents and official publications were accessed from relevant websites including the Department of Health, Social Care Institute for Excellence (SCIE) and www.disabilitynow.org.uk. Three areas of research were identified as relevant to the aim of this study: sex education for young people with learning disabilities, societal attitudes to such young people engaging in sexual relationships, and the issues arising for services and practitioners in managing inappropriate sexualised behaviours.

## Sex Education and Sexual Knowledge

In 2005 Murphy and Young reported that adolescents with disabilities seemed to be participating in sexual relationships without adequate knowledge and skills to keep them healthy and safe. This is reflected in a large scale survey of 1000 disabled people by

Disability Now UK, almost half of whom said they had not received any form of sex education at school. The majority (84 per cent) said they were not given guidance specific to disabled people and many had been discouraged from sex altogether (Choppin 2005).

Although these studies failed to differentiate between the types of disabilities young people experienced, they are supported by findings that focus specifically on those with learning disabilities. Simpson et al (2010) audited the number of referrals for 'inappropriate sexual behaviour' to a young people's learning disability team. Results showed that in most cases children with learning disabilities received little or no sex and relationship education or support, teaching staff struggled to address the sexual health needs of these young people, the available teaching resources were outdated and staff did not have the time, commitment or confidence to deliver them.

Teaching staff in Howard-Barr et al's study (2005) reported delivering only a modest amount of sex education and rated their professional preparation for covering the topic with this group of students as inadequate. Perhaps it is therefore unsurprising that Simpson et al (2006) suggest young people with learning disabilities have a limited understanding of sex and sexual health, and Isler et al (2009) report that adolescents with learning disabilities have very low levels of correct information about sex, and the stages of adolescent development. This is supported in a three-year project running from 2007-2010, undertaken by CHANGE, a national organisation that fights for the rights of people with learning disabilities. Results revealed that some young people with learning disabilities harboured serious misunderstandings in relation to sexuality, for example believing that gay sex was illegal (CHANGE 2010).

However where the provision of sexual knowledge is tailored appropriately there is some evidence that young people's capacity to make decisions about their sexuality can be improved (Dukes and McGuire 2009) and some young people are receiving sex education when they are in school (Healy et al 2009). The importance of appropriate and accessible sex education for young people with learning disabilities is particularly reinforced by studies that attest to children with a learning disability being at an increased risk of sexual and physical abuse and neglect (Allington-Smith et al 2002). Disabled children may be especially vulnerable to abuse as a result of receiving intimate care, possibly from a number of carers which may increase the risk of exposure to abusive behaviour. Additionally communication difficulties may limit their ability to tell others what is happening (Department of Health, 2006, para 11.27). Accessible sex education therefore allows young people with learning disabilities to learn to protect the privacy of their own body and themselves from abuse, unplanned pregnancy, or sexually transmitted diseases (Murphy and Young 2005).

Where young people do receive such education, attention needs to be paid to effective communication between parents and professionals. Garbutt (2008) reported that many parents of young people with learning disabilities did not know what sex education their children were being taught in school and expressed concern that they had to fight for information or felt unsupported by professionals.

## Societal Attitudes

Where literature has considered the views of young people with disabilities, their care givers and other interested parties regarding attitudes towards sexual relationships, there are conflicting results. Berman et al (1999) concluded that out of a sample of 29 young people the majority had hopes and desires for marriage, children and adult sex lives.

In contrast, the views of parents/carers and the wider society regarding these aspirations becoming a reality remain negative in modern culture and there is some evidence that this

is internalised by people with intellectual disabilities and contributes negatively to their attitudes regarding their own sexuality (Cuskelly and Bryde 2004). Indeed when Evans et al (2009) asked family carers of people with learning disabilities to outline the types of relationships they thought the individual was capable of engaging in, results showed a high acceptance of platonic friendship and non-intimate relationships but intimate or marital relationships were not considered as a possibility. Some parents and teachers were prepared to go as far as supporting involuntary sterilization as a form of contraception for young people with learning disabilities (Aunos and Feldman, 2002), whilst other research suggests that parents may assume that the sexuality of their learning disabled child is irrelevant because of their level of cognitive impairment (Morris, 2001). As young people develop it has been reported that parents may also fail to encourage age appropriate expressions of sexuality such as kissing (Giulio 2003), and when adolescents begin to respond to hormonal changes and sexual feelings, parents and professionals are often frightened by the emerging behaviour (Hallum 1995).

Other research has investigated non disabled people's attitudes towards specific sex acts and behaviours. The results of a study by Milligan and Neufeld (2001) suggest sex acts involving people with disabilities are viewed more negatively than when the same behaviours are considered in the context of a non-disabled person.

Morris (2001) reported that when adolescents with learning disabilities did have boy/girlfriends they did not have the opportunity to spend time alone with them. It seems that whilst some parents display positive attitudes towards the possibility of their children having fulfilling relationships at some stage in their lives they may also keep their children under constant supervision due to concerns regarding vulnerability (Garbutt 2008). This is supported by young people in the CHANGE survey who felt they did not have enough places to go to meet others. Teachers and parents concurred with this stating that young people with learning disabilities can become very isolated (CHANGE 2010).

## Inappropriate Sexualised Behaviour

The current literature also discusses the problem of inappropriate sexualised behaviour in young people with learning disabilities. Whilst some argue that masturbation is a normal behaviour through which adolescents with developmental disabilities learn about their sexual functioning (Murphy and Young 2005) a commonly reported concern is inappropriate masturbation when it occurs in public places (Hall and Hill 1996). A study undertaken by Fyson (2003) investigated the extent to which special schools were experiencing such sexually inappropriate behaviour, with results suggesting that this was a common occurrence and none of the special schools had a clear policy on how to respond. In the CHANGE study teacher and parents discussed this sensitive issue and teachers concluded that they often used techniques to redirect inappropriate masturbation such as placing a tray on a wheelchair to restrict access (CHANGE 2010).

It has been suggested that masturbation in public places by young people with learning disabilities may arise as they lack private, safe places to masturbate (Guilio 2003). As argued by Hingsburger and Tough (2002), where there is no privacy, there is no such thing as appropriate sexual expression. According to Hall and Hill (1996) young people with learning disabilities must be taught about the importance of privacy for such behaviours, a message supported by The Challenging Behaviour Foundation which offers advice on how to respond to inappropriate masturbation. An information sheet provided by The Foundation discusses difficult sexual behaviour and suggests that young men with learning disabilities can be supported to masturbate and if this behaviour occurs in school they should be directed to a private place (Thompson, undated).

Walsh (2000) supports this view, and proposes accepting and promoting appropriate masturbation. He goes on to state that adequate access to a private place may be required to prevent masturbation occurring in front of others. Within the learning disability literature the focus on managing such sexual behaviours seems to focus on young men and the issue of young women's sexuality seems to be ignored. McCarthy (1999) points out that lesbian sexuality in women with learning disabilities is one of the least researched and understood forms of sexual expression.

In summary it transpires that whilst policy and legislative developments are in place to support sex education for young people with learning disabilities there are still a number of practical and attitudinal barriers to be overcome before changes will embed in practice. As a result this study sought to establish whether in one local authority young people with learning disabilities were being allowed and encouraged to acquire a knowledge of sexual relationships. This was explored by investigating from the perspectives of young people, parents and professionals whether:

- appropriate sex education was received in school and staff's experiences of delivering this;
- parent's views on their child's future, in terms of sexual relationships, matched the hopes and aspirations of the young people;
- staff experienced inappropriate sexualised behaviours occurring in school and how they dealt with this.

## Methodology

This study was small scale in nature and designed to be exploratory in its approach in order to understand respondents' experiences in more detail. Individual semi-structured interviews were conducted with young people with learning disabilities and their parents and group interviews were conducted with professionals. This allowed some degree of triangulation of the qualitative data and comparison of the responses (Punch 2006). A qualitative design was deemed the most appropriate for the investigation as it aimed to elicit thoughts, feelings and experiences about what emerged from the literature as a sensitive topic that was rarely discussed openly (Rees 1997).

A purposive sampling strategy was employed in one local authority team for children with disabilities aged 0-18 years. Of the 155 children currently registered with the team the study sought to involve those within the age range of 11-16 as they would be in receipt of sex education in school. Young people with a learning disability were approached to participate if they had no associated physical impairment or condition on the autism spectrum. This was to establish whether some of the issues emerging from the literature applied to this specific group of young people. A total of seven young people met the criteria to participate and having received further information about the study four agreed to be interviewed along with their parents.

The sample of professionals approached to be interviewed consisted of twelve teachers and two public health nurses who worked in a special school that had close links with the local authority team. Both nurses and two of the teachers agreed to participate in the study and group interviews were conducted separately for the different disciplines. Information was provided to all participants explaining the nature of the study and seeking signed consent to their involvement. Information for the young people was produced in Communicate in Print ©, a system available worldwide where symbols are used to assist verbal communication.

The interview schedules were designed with reference to the literature reviewed and anecdotal information from young people and their parents who used the local authority services. Informal feedback from staff working in the special needs school informed the topic areas covered in the group interviews. The interview schedules were piloted prior to data collection with one young person, one parent and two professionals respectively and questions were amended according to feedback. The individuals who piloted the questions were not involved in the final study.

Consequently the interview schedule for the young people focused on questions associated with what they wished for in the future in terms of having adult relationships and children, in addition to their knowledge about sex and relationships. The interview questions for parents concentrated on their views regarding their child's future in terms of developing relationships, their views on sex education, and any support they received from professionals. Interview questions for the professionals explored what sex education occurs in school and whether it was adapted to the young people's level of understanding. In addition questions were asked regarding the occurrence of sexualised behaviours and how these were dealt with in practice.

## Data Analysis

All of the interviews were recorded and transcribed to allow for thematic analysis of the qualitative data (Joffe and Yardley 2004). The raw data was read and re-read to indentify themes that were then coded to indicate their belonging to a wider category (Denscombe 2007). The categories were then identified and refined by relating them to each other so that general themes could be established (Borgatti 1996).

## Ethical Considerations

Ethical considerations were taken into account at each stage of the research process and ethical approval for the study was obtained from the local authority and corresponding University where the authors were based. All potential participants were given information about the study prior to data collection and all had to give consent to take part knowing that all qualitative data obtained would be anonymised. Parents had to give their consent for their children to participate before the young people were approached. In addition all participants could view the questions they were going to be asked beforehand to ensure they were comfortable with them. Parents were able to view the questions that their children would be asked before agreeing they could take part. Parents were asked to indicate if their child required assistance to read the letters they would be sent and if so letters and information sheets were provided in Communicate in Print ©. The young people were familiar with this system as it is used in school and this method ensured they could understand the information they were being given and had the opportunity to choose for themselves if they wanted to be involved.

Given the literature reviewed it was recognised that the nature of this topic had the potential to cause distress, therefore participants were informed that they were free to withdraw from the study at any time and that arrangements were in place for professional support to be available if this became necessary.

In order to respond sensitively to potential distress experienced by the young people questions were adapted to their level of understanding and they were not asked directly to discuss their knowledge of sex. A further ethical consideration of the study was the potential for responses to indicate poor parenting or professional practice that could raise concerns for the young people's welfare. Participants were therefore advised that if such

information was disclosed the researcher would pass this information onto the relevant professionals. Participant's agreement to this was sought on the consent form.

## Results

All four young people in the study confirmed that they had received sex education in school. They said they had learned 'about how to make babies' (Young person, participant 2) and how their body will change and develop as they get older. However as identified in the literature (Simpson et al 2006; Isler et al 2009; CHANGE 2010) there seemed to be some fundamental misunderstandings about the information they had received. In particular the consequences of the act of sexual intercourse were not fully understood.

> They showed me at school that if I had sex and I go swimming my belly will get bigger (Young person participant 3)
>
> So if you've had sex what would cause your belly to get bigger? (Interviewer)
>
> Just if you go swimming (Young Person participant 3)

While all the parents thought that their children should receive sex education in school they reported that they did not know the content of what was taught, although they believed it would cover everything that non-disabled children in mainstream schools would learn. Only one parent had approached the subject of sex with their child, the others being of the opinion that their children would not understand.

> I haven't spoken to him about development, I couldn't explain it to him as he won't understand (Parent participant 1)
>
> It's no good me talking to her, she won't take any notice (Parent participant 4)

The teaching staff advised that all topics taught in sex education were adapted to the young people's level of understanding, and that although topics were similar to those taught in mainstream, information is broken down and often repeated. Public health nurses reported working collaboratively with the teachers to deliver sex education and would then offer support to individual students if necessary. However both groups described how they had never had any specialised training in how to deliver sex education to young people with learning disabilities and had devised the majority of the resources they used themselves.

> We have what teachers have pulled together, there's no centralised resource base or standardised resource package that all the special schools use. Resources are what we need (Teacher participant 1)

Teaching staff concurred that more resources would be beneficial to improve sex education, whilst the public health nurses stated they would benefit from being able to communicate with the young people using different methods such as Makaton.

Both professional groups were keen to stress that the young people with learning disabilities did retain information and learn from sex education lessons and that despite the lack of resources the professionals were confident in their ability to facilitate sex education.

In terms of sexualised behaviour in school teachers advised that kissing and touching were common, often occurring between young people of the same sex:

> In the toilets we might get kissing or touching occurring, this is sometimes same sex (Teacher participant 1)

As anticipated from the literature review masturbation was reported as a common occurrence. Teachers and public health nurses stated this was more common in boys, occurring only occasionally in the girls. Both groups concurred that the school's policy to respond to such behaviour was to show the young person to a private room:

> If you don't let them go somewhere private and do it then they won't stop, they would just do it anyway (Public health nurse participant 2)

The professionals then provided guidance on the importance of privacy for such behaviour and it was felt that these lessons were effective.

Interestingly staff's confidence in discussing sex and behaviour did not extend to education about close personal relationships. This was an issue that all respondents in the study struggled with for a variety of reasons. All the young people said they had boy/girlfriends at the time of the interview or had in the past. One of the young people summed up their need to know more:

> I would like to learn more about relationships, like having close friends, special friends that is (Young person, participant 4)

However the teacher's view was that:

> Although we may teach them things in school as best we can I agree that these children don't get the opportunity to develop a relationship (Teacher participant 2)

All parents stated that their child had a boy or girlfriend at some point and all indicated they had no concerns about this and would allow them to spend time together outside of school. However this was because parents did not think their child would have any intention of engaging in a sexual relationship:

> Yeah she has, she's got a boyfriend now, but by boyfriend its not like you and me think of a boyfriend…………What we think of and what she thinks is very different you know, when it comes to boyfriends, she wouldn't be getting up to anything (Parent participant 4)

School staff and parents faced the dilemma of restricting relationships in school time, whilst understanding that young people with learning disabilities don't get the opportunities to develop relationships outside the school environment in the same way as non-disabled young people as they are rarely left alone:

> That's very difficult. Personally I accept that they can and should happen but I don't think they should within school. It's about judging how far things should go. I'm quite happy for them to be girlfriend and boyfriend but not in school time (Teacher participant 1)

> I feel strongly that they don't get the opportunity to develop their relationships as other young people do. These young people are never left alone, they have no chance to explore relationships for themselves (Teacher participant 1)

> Where apart from school would he meet a girlfriend, there's scarce girls at school. I would like him to have the opportunity to meet more girls. There is a lack of social outlet, the chances of meeting a girl are very scarce (Parent participant 1)

Parents and professionals agreed that young people with learning disabilities found it hard to grasp the concept of relationships and all respondents raised the issue of the young people having a number of boy/girlfriends at any one time. This appeared to be significantly different to their non-disabled contemporaries:

> My boyfriend's at college, I met him through my ex, I've had 14 boyfriends altogether (Young person Participant 4)

> Grasping the concept of only being with one single person at a time is hard for them. If you ask some of the girls they will list a number of boys they have decided are now their boyfriend (Teacher participant 1)

> The kids always have girl and boyfriends, that's fine with us as long as there is no cause for concern (Public Health Nurse participant 2)

Despite their misgivings all the parents reported that they would like their child to have a loving relationship in their future although two said they thought this was unrealistic. All the parents stated they did not think their child would have children or that they should have the opportunity to achieve this because they would be unable to care for children of their own:

> He would not have the ability to raise children, he's just a little toddler in his head (Parent participant 1)

In contrast all of the young people said they wanted a partner when they were older and three out of four said they wanted children. Interestingly the one who didn't state this was because her mother did not think she would be able to cope:

> No, me mam doesn't want me to, she doesn't think I will be able to look after them (Young Person participant 2)

## Discussion

The study was designed to be small scale and exploratory as it involved young people, their parents and professionals from only one local authority, therefore the findings cannot be generalised beyond this population. If the research was to be replicated it would be beneficial to interview a larger number of participants across several geographical areas so that results would be more representative of young people with learning disabilities as a whole.

The subject area was sensitive and some of the young people may have found talking about sex and relationships uncomfortable. Even though Communicate in Print © was used to assist communication some of the responses from the young people were inarticulate, with their answers deviating from the original question. This is a challenge for

qualitative research that involves people with learning disabilities, as identified by Booth and Booth in 1996. This suggests that other modes of communication may need to be explored to ensure respondents have understood fully the questions they are being asked in order that their responses can be considered valid and reliable. During two of the interviews with young people in their homes their parents came back into the room whilst the interview was taking place. This may have had a negative impact on the young person's responses and suggests that there is a balance to be struck between conducting interviews in a familiar environment, whilst also giving the young people the opportunity to discuss their responses in the absence of their care givers.

Notwithstanding the limitations, the findings support Healy et al (2009) that young people with learning disabilities do receive sex education in school and that in this local authority the needs of this group are being considered with government legislation and guidance being adhered to (Department of Education and Employment, 2000). Both teachers and the public health nurses described the occurrence of sexualised behaviours as frequent, ranging from kissing and touching to public masturbation. The policy for dealing with the latter was to show the young person to a private room reflecting the guidance of the Challenging Behaviour Foundation (Thompson, undated) and Walsh (2000). The fact that staff back up this strategy with specialist sex education sessions about the importance of privacy is positive and a credit to the school. It also contradicts the findings reported by CHANGE (2010) that teachers often used techniques to curb inappropriate masturbation with no explanation.

Professionals are committed to providing information in a way that young people can understand and believe that they can learn from these lessons. However although the biological aspects of sex and development are being addressed some young people still harbour misunderstandings about the information they are given. In respect of emotional relationships staff and parents struggle to educate young people effectively even though young people say this is an area they want to learn more about.

While staff are confident in their ability to deliver sex education a lack of educative resources and training to assist them in their role is evident. This supports the findings of Simpson et al (2010). Parents also regard the delivery of sex education to be largely the domain of the education system. Whilst this may be appropriate it is clear from the study that parents and staff share similar concerns and issues. Better quality and more accessible resources could enable teachers to involve parents in the education process particularly outside school time in respect of relationship issues.

All the young people in the study had or had recently had a boy/girlfriend which supports Guilo (2003) that they have the same requirements for love and affection as non-learning disabled youngsters. On a positive note staff attitudes towards the young people engaging in relationships appeared to be liberal and accepting. That all the young people wanted a partner when they were older and the majority wanted children supports Berman et al (1999) that adolescents with disabilities have hopes and desires for marriage, children and adult sex lives. However these aspirations do not seem to be shared by the young people's parents, the majority of whom had never spoken to their child about sex and relationships and resisted the idea of their children having children of their own. These attitudes may contribute to the internalisation of negative messages about young people's sexuality as found by Cuskelly and Bryde (2004).

Further support for this is that although parents did not seem to have any concerns about their children being in a relationship, or spending time with a partner outside of school, this was primarily because they did not consider their child's relationship to be sexual in any way. This concurs with Morris (2001) who suggested parents may assume the sexuality of their learning disabled child is irrelevant because of their level of cognitive impairment.

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However figures from a borough in the West Midlands in 2005 revealed that 28 per cent of teenage mothers had some form of learning disability (Heer 2008). This suggests that parents may be misguided in their assumptions and may need more support to talk to their children about sex and relationships in more detail.

Overall the findings suggest that when relationships are accepted young people still have difficulty facilitating them. In accordance with Valuing People (DH 2001) it seems that more support needs to be available to assist young people in this regard. The provision of safe spaces where young people with learning disabilities are able to socialise with others in a supportive environment but not one where they are not under constant supervision appears to be a current gap in today's society.

Following on from the study, the children's disability team where this research took place are currently developing a programme of tools and information that can be used in the sex education of young people with learning disabilities. The results of this research suggest that such tools are needed by professionals alongside more specialist training in this particular area. In addition parents need to be supported to communicate with their children about sex and relationships and it would be beneficial if resources could be developed that children could take home from school in order to encourage educative strategies between parents and professionals, particularly with regard to personal relationships.

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