

Editorial

Welcome to this Autumn 2008 edition of *Research, Policy and Planning*. We open with a detailed paper by Chih Hoong Sin and colleagues that brings close critical scrutiny to the impact of regulatory fitness requirements regarding disabled people studying, qualifying, registering and working in social work. Their investigation, undertaken while based at the Disability Rights Commission, constitutes a comprehensive review of legislation, regulation and statutory guidance governing the social work profession and gives much food for thought about a number of perceived shortcomings in policy and practice.

The disability theme continues with the second article, from Chengqiu Xie and associates, concerning the results of a national study looking at the management of care for people with physical and sensory disabilities in England. Variations were found in aspects of care management arrangements and it is suggested that, in some respects, services are less advanced for this user group than for people with learning disabilities. A number of key insights arise from the study that can help inform decision-making in this field and which can guide future evaluatory studies that the authors argue are much needed.

Matt Baumann and colleagues explore closely the views of key professionals regarding the implementation of the reimbursement scheme - part of the Community Care (Delayed Discharges) Act 2003. The research was undertaken at sites where performance in terms of rates of delayed discharge was already effective and the article offers valuable guidance around good practice derived from their study into the early working of the reimbursement scheme. The team's work will be of much interest to those involved in implementing the scheme and to those with a role in discharge arrangements.

Next, Kay Caldwell and associates offer valuable illumination of the benefits of action research as a key strategy for promoting the involvement of older people as service consumers in health research. Their paper examines the practical and ethical complexities of user and researcher joint involvement in researching the service experience. Their discovery and discussion of shared and divergent perspectives of consumers and researchers makes for compelling reading and will be highly relevant to those engaged in, or planning to use, action research to evaluate practice and policy.

Finally, and highly pertinent to our 'credit crunch' times, Mark Drakeford and Lee Gregory review the role of credit unions and their diversification in Wales in response to new 'market' demands. Their study casts light on the much neglected world of the economically marginalised. Their original research into new credit union products and the risks and benefits in financially helping families reveals a rarely glimpsed credit-support system at work. It is one that is being called increasingly to assist ever more adults and children at the margins of economic wellbeing caught in a spiral of deepening money problems.

Last but not least, we are very pleased to include reviews of five new and very different books that address a range of topical issues in social care. One text, 'Understanding Social Work Research', should be of wide interest to students, academics and practitioners alike. If there are any books that you would like to see reviewed in future editions of the Journal please let us know and we will do our best to include these.

As the new editorial team, this is our fourth edition and we continue with our efforts to provide a varied selection of articles and reviews about the pressing issues of contemporary social care across the UK. We very much intend that these will be of relevance to the broad spectrum of SSRG members and our many other readers here and abroad with interests in policy, practice and research. As ever, we welcome your comments, critical as well as positive, as to how we are doing so that we can more fully meet your expectations. And, as always, if you would like to submit an article yourself or review a book, we would be pleased to hear from you. Contact details and submission guidelines can be found at <http://www.ssrge.org.uk/publications/rpp/index.asp>.

With best wishes from the editorial team: Sue Harrington, Greg Mantle, Andy Pithouse and Peter Scourfield

Professional regulation and disability equality: challenges for disabled social work students and professionals

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Abstract

This article reports on the Disability Rights Commission's Formal Investigation into the impact of regulatory fitness requirements on disabled people studying, qualifying, registering and working in social work. It presents a comprehensive review of legislation, regulation and statutory guidance governing the social work profession, identifying requirements for physical and mental fitness. These fitness descriptors and definitions are often vague and their implications in relation to disability unclear. The implementation of these requirements in practical decision-making within the higher education and employment contexts is explored. Findings point to inconsistent practice with ad hoc procedures involving a multitude of different decision-makers. Evidence submitted by key stakeholder organisations to a formal call for evidence attests to the fact that there are anxieties in relation to how regulatory fitness requirements can or should be implemented in practice. It is argued that generalised fitness requirements are inappropriate and potentially discriminatory. Instead decisions around fitness should be based on the requirements of specific jobs, with consideration of reasonable adjustments where relevant. Public bodies are encouraged to update their policies and procedures, bringing them in line with developments in disability and wider equalities legislation. In addition, a more proactive and positive approach towards the promotion of disability equality is required to shift attitudes.

Keywords: Disability Rights Commission, Formal Investigation, regulatory fitness requirements, disabled people

Introduction

In September 2007, the Disability Rights Commission (DRC) of Great Britain concluded a year-long Formal Investigation (FI) into the impact of regulatory fitness standards on disabled people studying, qualifying, registering and working in three professions, one of which was social work (DRC, 2007a). The main components of the FI are summarised in the table in Appendix 1 (page 85).

Professional regulation is a means of ensuring standards are maintained and, for a profession like social work, to protect service users or other members of the public

who are often deemed 'vulnerable' in some way. There have been a number of initiatives within Britain to encourage the diversification of workforces in a range of professions (Department of Health, 2000a; Scottish Executive, 2005). However, the interaction between such strategies and existing forms of professional regulation has been under-scrutinised. Yet there is evidence to suggest that elements of professional regulation have the potential to operate in ways that militate against genuinely inclusive workforce strategies.

In relation to disabled people, the DRC handled a number of cases involving professional bodies, employers and higher

education institutions struggling to enforce the law requiring them to regulate entry into professional occupations. Examples included cases relating to social work (see a review of DRC cases by Sin *et al.*, 2006). There are a number of barriers confronting disabled people seeking entry into the social work profession as well as remaining within employment.

This article reports on the types of fitness requirement that exist within the regulation, legislation and statutory guidance governing the social work profession and examines their implications for disabled people. There are a number of regulatory fitness requirements using imprecise definitions and descriptions of physical and mental fitness. Perhaps confusingly, there are significant differences across the countries of Great Britain. In addition, the ways in which such requirements are implemented 'on the ground' are revealed to be variable and inconsistent within both the higher education and employment contexts. This can unwittingly discriminate against disabled people. Some of these experiences from the perspective of disabled people are documented in an independent piece of research conducted for the FI by Stanley *et al.* (2007) and readers are directed to the full report for further details. The article concludes with some implications and recommendations for policy and practice.

Social work and disability

Social work in Great Britain has close association with anti-oppressive and anti-discriminatory theory and practice (Dalrymple & Burke, 1995; Dominelli, 2002; Thompson, 2006). While there may be slight differences in terminology used, the broad approach has been underpinned by a particular orientation: that between social workers and social work clients, particularly a range of vulnerable service users (Wilson & Beresford, 2000). As a caring profession, social work has not as yet paid much attention to disabled people as qualified and

competent professionals. In fact until the mid 1990s relatively little was known about staff, in general, working in social work and social care (Balloch *et al.*, 1999).

There have since been important studies reporting on the diversity and equality issues within the social work and social care workforce. For instance, gender issues within the workforce have been scrutinised by Davey (2002); with McLean (2003a) and Fisher (2006) contributing important but often neglected perspectives on men employed within social work and social care. The ethnic composition of, and racism within, the workforce has also attracted significant attention (e.g. Brockmann *et al.*, 2001; Butt, 2001). There has also been some work on social workers from the perspective of the sexual orientation of staff (McLean, 1998), and also about disabled social workers (McLean, 2001 & 2003b) although there has been more focus upon disabled social work students (Baron *et al.*, 1996; Cooley & Salvaggio, 2002; Crawshaw, 2002; Sapey *et al.*, 2004).

There have also been a number of studies on diversity of the social work student population. Hussein *et al.*'s (2007) study of progression rates among students studying for the DipSW in England found that male students, students from a black and minority ethnic group, and students with a self-reported disability have poorer progression rates.

In general, however, Crisp *et al.*'s (2005) review of literature relating to social work education and training found that few key texts included any or adequate coverage of equality and diversity issues. Coverage, where it exists, was highly variable in depth and quality.

The portrayal and conceptualisation of social work and social workers has pitched vulnerability more often as a characteristic associated with 'clients'. The DRC's FI reported evidence that:

the culture within ... social work appears to be one where there is discomfort about boundaries between professionals and ... clients being blurred. (2007a, p.206)

In terms of disability, the approach in many caring professions is still very much in terms of disabled people as the focus of care and caring (Siepel, 1994). The fact that disabled people can be practitioners within caring professions is still not taken seriously enough. As Sapey *et al.*, (2004) noted:

disabled people are at times expected to remain in the position of being helped, rather than becoming a helper. (p.15)

Against this context, it is perhaps unsurprising that Sin *et al.* (2006) observed that despite the:

many claims in the literature...that disabled people are under-represented in social work ... [there is] limited empirical evidence put forward to support these claims. (pp.10-1)

There is a paucity of monitoring data on disability within the social work profession, and an acknowledgement from some organisations that existing data may be unreliable (Hurstfield *et al.*, 2004). This is in spite of initiatives to encourage a more diverse social care workforce.

As part of the DRC's FI, a formal call for evidence was issued, targeting key organisations within social work, amongst others. As part of the call for evidence, social work regulatory bodies were invited to submit monitoring statistics on disabled employees, students and registrants. Regulatory bodies were additionally asked to provide such information in a way that allowed cross-referencing the 'disability' variable with other key demographic variables such as sex, age and ethnicity.

Submitted responses indicated that none of the regulatory bodies conducted

comprehensive monitoring by disability. Where available, coverage was selective and patchy. Data were not cross-referenced with other key demographic variables therefore inhibiting more detailed analyses. In addition, disability monitoring appears to be a recent phenomenon.

In England the General Social Care Council's figures demonstrated that there were 1,489 disabled qualified social workers comprising 1.95% of all qualified social workers in 2006. The Care Council Wales's data showed that there were 94 disabled social work registrants – 2.15% of social work registrants in Wales in 2006. The Scottish Social Services Council's figures showed that there were 160 disabled registered social workers comprising 2.40% of all registered social workers in Scotland in 2005 (DRC, 2007a, p.208).

Disability as risk within the social work profession

The social work profession is characterised by anxieties about risk, sparked in part by high-profile criminal inquiries. In Britain, for example, the tragic circumstances surrounding the death of Victoria Climbié raised, once more, the issues of risk and regulation.

While gross failures of the system are rare, their impact on public confidence and the construction of professional identities of social workers (both by members of the public and by the profession itself) has been amplified by the media. Regulation regimes have evolved to reflect, to a large extent, influential forces on policy such as public opinion and the market (Hood *et al.*, 2001). Professional regulation has developed to be diagnostic and defensive in an attempt to screen out risks at the earliest possible stages (Tanner, 1998).

The identification and management of risk have become increasingly important and formalised. Alaszewski and Manthorpe

(1998) noted that until the 1980s, little attention was paid to the way in which welfare institutions manage risk. However, risk has now been studied extensively in relation to professional practice (e.g. Alaszewski *et al.*, 1997; Titterton, 2004). Risk assessment and risk management have become *de rigeur* across social care and health professions, with tomes published to guide practitioners through the principles, policies and procedures (e.g. Owen & Pritchard, 1993; Kemshall & Pritchard, 1997).

The conceptualisation of, and discourse around, risk has posited clients and service users as being vulnerable to harm. Regulation, in the context of the social work profession, has developed, in part, to manage perceived risks and to protect the public while ensuring a high quality of service.

Two contrasting conceptualisations of risk apply to disabled people. First, there are risks *to* disabled people as a result of their disability. This is intimately related to the portrayal of disabled people as vulnerable.

Second, disabled people are portrayed *as* risks to themselves and to others. Disability and impairment are understood here as ‘defects’ that have the potential to cause disabled people to bring harm upon themselves, or to have an impaired ability to avoid harm. This ‘defect’ also has the potential to endanger others (DRC, 2007b). In this context, disabled people seeking entry or working within the social work profession can be perceived to be a problem.

The following discussion draws on various sources of evidence generated by the FI to demonstrate how certain methods of managing risk through professional regulation in social work can introduce blanket exclusions that have the potential to bring about disability-related discrimination. In addition, the interaction between key provisions contained within disability

legislation and the implementation of regulatory requirements within the higher education and employment contexts can often be unclear (Sin *et al.*, 2006).

Generalised regulatory fitness requirements

Under the Care Standards Act 2000 (Department of Health, 2000b), the General Social Care Council (GSCC) in England and the Care Council for Wales (CCW) have statutory duties in relation to registering and regulating social care workers (including social workers), and in publishing codes of conduct and practice in relation to them.

In addition to requirements for training, conduct and competence, the Act requires the Councils to be satisfied that an applicant must be of “good character”, as well as “physically and mentally fit to perform the whole or part of the work of persons registered in any part of the register to which his application relates” before he or she can be registered.

For registration as a student, regulation 4(4) states that a student entrant must provide evidence of good character and conduct; and physical and mental fitness to practise as a social worker. This makes no reference to “part of the work of social worker or social care worker” and therefore seems more absolute in its requirement.

For Scotland, on the other hand, the Scottish Social Services Council (SSSC) was established by the Regulation of Care (Scotland) Act 2001 to promote high standards of conduct and practice among social service workers and in their education and training, and to regulate entry to the register. The SSSC is required not to register a person unless satisfied that the applicant meets the statutory requirements of “good character” and competence and meets the Council’s educational and training requirements. This is significantly different to the requirements in England and Wales,

as there is no requirement for physical and mental fitness.

In addition, the Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002 (Scottish Executive, 2002) specify that providers of care services shall not employ any person in the provision of a care service if that person is “not physically and mentally fit for the purposes of the work for which the person is employed in the care service”. This concerns specific work at a specific service, rather than imposing a condition for entry to the profession, training, registration or generally for employment (Ruebain *et al.*, 2006).

Fitness decision-making in practice

The formal call for evidence issued by the FI identified the fact that most of the representatives responding from key stakeholder organisations in social work felt that the regulatory framework was unclear in terms of how disability issues were addressed, and how concerns relating to disabled people were handled. (Sin *et al.*, 2007a). In particular, certain concepts and terminology used to describe and define ‘fitness’ were felt to be vague (Sin, 2007a).

In a separate piece of independent research commissioned as part of the FI, Wray *et al.* (2007) found that, for higher education institutions (HEI), there was:

a clear link between the regulations, the guidance issued by the regulatory bodies and how decisions are made about fitness ... education providers are following the current guidance laid down by the regulatory bodies. ... Their practice is unlikely to change until the information provided by regulatory bodies is updated. ... Social Work appeared to be at a particular disadvantage in relation to availability of current guidance. (p.11)

The imprecision in terminology employed to describe and define fitness within the regulation coupled with the lack of clear procedural guidance for those with responsibilities for implementing such requirements in practice can have important implications. For example, in a formal submission to the FI’s call for evidence, a respondent from a higher education institution wrote that:

These studying, qualifying, registering and working guidelines and frameworks, fail to provide the social work team here at the university with any clear guidance on how to support the students in light of any disability related disclosures, nor does it offer any practical guidance to our placement process or providers in the area of work placements. In fact, the outcome of the registration process is not filtered through effectively to the relevant people at the university.

There is confusion over what is required in assessing fitness, as well as who should be responsible for such decision-making. This leads to a variety of self-initiated, and often *ad hoc*, management strategies with a number of different outcomes for disabled people.

Structures and procedures for formal and informal fitness assessments in practice are often unclear and inconsistent. Most organisations responsible for implementing fitness requirements rely on a variety of individuals to interpret what the regulations mean when issues relating to disability arise. Responses to the call for evidence demonstrate that organisations relied on a mixture of occupational health (OH) professionals, human resources staff, and admissions staff (Sin *et al.*, 2007a).

Research into decision-making within the higher education context identified that academic staff, OH professionals, human resources staff, university disability officers/advisers, the regulatory body, and

the disabled person him/herself were involved in decision-making around fitness (Wray *et al.*, 2007).

Independent research commissioned in support of the FI on similar decision-making processes within the employment setting also identified the significant involvement of OH professionals. In addition, managers, human resources staff and others were also involved (Fong *et al.*, 2007).

The role of OH professionals in fitness assessments in a range of settings is of interest. Wray *et al.* (2007) found that, at the application stage, 56% of responding HEIs indicated that OH professionals were relied upon to make decisions around an applicant's fitness. That such practice exists and is seemingly rather prevalent is interesting given that the social work profession does not have any explicit requirement contained within its regulatory framework for relying on OH advice. In comparison, while the FI found that reliance on OH was prevalent among HEIs for nursing and for teaching, this was not surprising given that nursing in Britain and teaching in England and Wales have specific regulatory requirements for OH professionals to be consulted in fitness assessments.

Apart from the application stage, Wray *et al.* (2007) additionally found that only around half of responding HEIs with social work programmes stated they had a formal procedure for making decisions regarding fitness of students whilst they were on programmes. That not all HEIs have such procedures in place is cause for concern as the needs of disabled students may change through time. Furthermore, students accepted onto social work programmes may also experience the onset of disability during the programme. There is also the possibility that certain impairments may only be identified after acceptance onto a programme and/or after a programme has commenced.

It is thus unclear how some HEIs handle fitness issues that arise after the application stage. Clarity of procedures and transparency of processes are paramount as disabled students need to be supported on an ongoing basis, particularly if there are changes to needs for reasonable adjustments.

In relation to employment, Fong *et al.* (2007) similarly identified the significant role of OH professionals in fitness assessments. At the pre-employment stage, almost three-quarters of responding social work employers relied on OH professionals in decision-making around fitness. In fact, OH professionals are the single group most relied upon to make such decisions. In comparison, only a quarter of social work employers relied on human resources staff for fitness assessment and less than 5% involved the relevant social services directorate.

The involvement of OH professionals should not, however, be taken to mean that they are deployed consistently 'on the ground'. Indeed, the FI uncovered diverse approaches in how OH professionals operate and how their roles were integrated within the wider structure of an HEI or an employing organisation.

There was a sense of disquiet expressed by some representatives who submitted formal evidence on behalf of key organisations in relation to the perceived potential for uncritical reliance on OH advice. In addition to the obvious risk that disability may be medicalised, there is also the danger that decisions about fitness are delegated to OH professionals who may have little knowledge of exactly what the regulatory frameworks are for the profession. This risk is particularly real in situations where the OH function may not be working in close collaboration with employers or educational institutions over such decisions.

In a formal submission to the FI, an organisation stated that:

it is not possible to predict the impact of the disability at any one time. ... It is important that each case is treated on its own merits. It is the impact of a condition that needs to be judged in relation to the requirements of a particular post...

Instead of using information about a person's disability to predict his or her chances of success in completing a course or in securing and retaining employment, the impact of an individual's physical or mental condition needs to be assessed in relation to the requirements of a specific job. The Codes of Practice issued by the DRC provide a number of examples involving the provision of relevant reasonable adjustments in both the higher education and employment contexts (DRC, 2004 & 2007c).

Indeed, the responsibility to consider providing reasonable adjustments is stated clearly within the employment provisions of the Disability Discrimination Act (DDA) which place the responsibility of making decisions about employment with the employer, and not purely with the medical adviser. The DDA Code of Practice states:

where medical information is available, employers must weigh it up in the context of the actual job, and the capability of the individual. An employer should also consider whether reasonable adjustments could be made in order to overcome any problems which may have been identified as a result of the medical information. (DRC, 2004, paragraph 6.15)

It is therefore important for OH professionals to work closely with employers and HEIs around reasonable adjustments.

Regardless of who is involved in the processes and structures of fitness

assessment, it is clear that the full responsibility for decision-making was felt to fall squarely on the organisation itself with little support from regulatory bodies (Sin *et al.*, 2007b). This came across very strongly in the formal evidence submitted to the FI by key stakeholder organisations within the profession. There is a distinct sense of anxiety expressed by representatives from these organisations in relation to appropriate methods of reconciling regulatory requirements and professional standards with adequate support for disabled people, as the following extract from the written submission of a representative from an HEI demonstrates:

The difficulty the social work team are facing with students with dyslexia is how to implement the support they require, are entitled to and receive whilst at university with academic work and balancing this out with the demands of the job and trying to assess students' ability to independently carry out the duties and expectations of their social work role to agency standards.

Wider implications

Risk management has become the order of the day in a number of professions and there have been concomitant efforts at professionalising workforces and extending regulation. The UK Government has recently proposed that all statutorily-regulated health professionals have 'revalidation' arrangements in place to facilitate professionals periodically demonstrating their continued fitness to practise (Sin & Fong, 2007a). The Government is also considering the regulation of non-medical healthcare professionals, with the aim of standardising regulation, and giving the Council for Healthcare Regulatory Excellence a pivotal role. There are also movements in professionalising the children's services workforce (DfES, 2005).

A cursory look at the regulation around other regulated health professions reveals similarly varied and potentially misleading descriptors of fitness which have a statutory basis (see Sin & Fong, 2007a & 2007b). Similarly, the extent to which the DDA is acknowledged and dealt with in relevant legislation is highly variable. There is thus a real concern that the plethora of legislation, regulation and guidance in a number of other professions may not be DDA-aware nor compliant.

While the DRC's FI focused on the public sector, there is an array of regulations covering care home registration, including fitness standards for managers and employees of care homes. It is of note that none of these registration conditions make any reference to fitness being assessed in a way that demonstrates having due regard to the provider's obligations under the employment provisions of the DDA. This includes conditions for their employees who may be care workers or occasionally social workers. This is significant for disabled people seeking employment in this sector since many providers are small organisations who may have less awareness of their DDA obligations (Ruebain *et al.*, 2006).

Conclusion

The Chair of the GSCC has recently written to the Minister of State for Health Services asking for the requirement to be '*physically and mentally fit*' to be removed. There has been unease about this requirement for some time and, perhaps partially as a result of the evidence gathered by the DRC's FI, the GSCC now considers the requirements to be an unnecessary and discriminatory barrier (GSCC, 2008).

Public authorities are now required to respond to legislation designed to promote disability equality (DRC, 2006). The disability equality duty (DED) which came into force in December 2006 places a

positive duty on public bodies to have due regard to:

- the need to eliminate unlawful disability discrimination;
- the need to eliminate harassment of disabled people;
- the need to promote equality of opportunity between disabled persons and others;
- the need to take steps to take account of disabled people's disabilities even where that involves treating disabled people more favourably;
- the need to promote positive attitudes towards disabled people; and
- the need to encourage participation of disabled people in public life (see DRC, 2006, p.5).

The DED covers all aspects of public sector activity applying to policy-making, decision-making, service provision, procurement; and to public bodies as employers and as education providers. The implications of the DED are therefore profound, although most public bodies are likely to have underestimated its full significance (Sin, 2007b). All public bodies should therefore update their policies and procedures in light of developments in disability (and wider equality) legislations.

While legislation plays an important role, it needs to be backed up by more proactive and positive approaches towards disability equality that transform cultures and behaviours in a meaningful and sustainable manner throughout the profession (see RADAR, 2007, for case studies of public bodies that have demonstrated good practice in relation to this). This prevents a negative compliance approach towards equality and diversity (O'Conneide, 2003), and shifts people away from the misconception that equality and diversity only applies to various 'minority' groups. Instead, positive approaches towards equality benefit everyone.

References

- Alaszewski, A. & Manthorpe, J. (1998) 'Welfare agencies and risk: the missing link?', *Health and Social Care in the Community*, **6**(1), pp.4–15.
- Alaszewski, A., Walsh, M., Manthorpe, J. & Harrison, L. (1997) 'Managing risks in the city: the role of welfare professionals in managing risks arising from vulnerable individuals in cities', *Health and Place*, **3**(1), pp.15–23.
- Balloch, S., McLean, J. & Fisher, M. (eds.) (1999) *Social Services. Working Under Pressure*, Bristol: Policy Press.
- Baron, S., Phillips, R. & Stalker, K. (1996) 'Barriers to training for disabled social work students', *Disability & Society*, **11**(3), pp.361–77.
- Brockmann, M., Butt, J. & Fisher, M. (2001) 'The experience of racism: black staff in social services', *Research, Policy and Planning*, **19**(2), pp.1–11.
- Butt, J. (2001) *Issues of 'Race' and Ethnicity and the Experience of Violence in Social Care*, London: REU.
- Cooley, B. & Salvaggio, R. (2002) 'Ditching the 'dis' in disability: supervising students who have a disability', *Australian Social Work*, **55**(1), pp.50–9.
- Crawshaw, M. (2002) 'Disabled people's access to social work education – ways and means of promoting environmental change', *Social Work Education*, **21**(5), pp.503–14.
- Crisp, B.R., Anderson, M.R., Orme, J. & Lister, P.G. (2005) *Learning and Teaching in Social Work Education: Textbooks and Frameworks on Assessment*, London: Social Care Institute for Excellence.
- Dalrymple, J. & Burke, B. (1995) *Anti-oppressive Practice, Social Care and the Law*, Buckingham: Open University Press.
- Davey, B. (2002) 'Management progression and ambition: women and men in social work', *Research, Policy and Planning*, **20**(2), pp.21–34.
- Department for Education and Skills (DfES) (2005) *Common Core of Skills and Knowledge for the Children's Workforce*, London: DfES.
- Department of Health (2000a) *Looking Beyond Labels: Widening the Employment Opportunities for Disabled People in the New NHS*, London: Department of Health.
- Department of Health (2000b) *Care Standards Act 2000*, HSC 2001/011, London: TSO.
- Disability Rights Commission (DRC) (2004) *Disability Discrimination Act 1995. Code of Practice. Employment and Occupation*, London: DRC & TSO.
- Disability Rights Commission (DRC) (2006) *Doing the Duty: An Overview of the Disability Equality Duty for the Public Sector*, London: DRC.
- Disability Rights Commission (DRC) (2007a) *Maintaining Standards: Promoting Equality. Professional Regulation Within Nursing, Teaching and Social Work and Disabled People's Access to These Professions*, London: DRC.
- Disability Rights Commission (DRC) (2007b) *The Disability Agenda. Creating an Alternative Future*, London: DRC.
- Disability Rights Commission (DRC) (2007c) *Disability Discrimination Act 1995. Code of Practice Post-16. Code of Practice (revised) for Providers of Post-16 Education and Related Services*, London: DRC & TSO.

- Dominelli, L. (2002) *Anti-oppressive Social Work Theory and Practice*, London: Palgrave Macmillan.
- Fisher, M. (2006) 'Man-made care: community care and older male carers', *British Journal of Social Work*, **24**(6), pp.659–80.
- Fong, J., Sin, C.H., with Wray, J., Gibson, H., Aspland, J. & Data Captain Ltd. (2007) *Assessments and Decisions Relating to 'Fitness' for Employment within Teaching, Nursing and Social Work: A Survey of Employers*, London: DRC.
- General Social Care Council (GSCC) (2008) *Media Release (9 January 2008): Remove Requirement for Social Workers to Declare Health Conditions*, London, GSCC.
- Hood, C., Rothstein, H. & Baldwin, R. (2001) *The Government of Risk: Understanding Risk Regulation Regimes*, Oxford: Oxford University Press.
- Hurstfield, J., Aston, J., Mitchell, H. & Ritchie, H. (2004) *Qualifications Bodies and the Disability Discrimination Act*, Institute for Employment Studies Report 417, Brighton: Institute for Employment Studies.
- Hussein, S., Moriarty, J., Manthorpe, J. & Huxley, P. 'Diversity and progression among students starting social work qualifying programmes in England between 1995 and 1998: a quantitative study', *British Journal of Social Work*, Advance Access published 1 February 2007, doi:10.1093/bjsw/bcl378.
- Kemshall, H. & Pritchard, J. (1997) *Good Practice in Risk Assessment and Risk Management. Volume 2: Key Themes in Protection, Rights and Responsibilities*, London: Jessica Kingsley.
- McLean, J. (1998) 'Anti-discriminatory practice: gender, sexuality and disclosure by social services staff', *Issues in Social Work Education*, **18**(2), pp.75–81.
- McLean, J. (2001) 'Employees with long-term limiting illnesses or disabilities', *Managing Community Care*, **9**(6), pp.44–7.
- McLean, J. (2003a) 'Men as minority: men employed in statutory social care work', *Journal of Social Work*, **3**(1), pp.45–68.
- McLean, J. (2003b) 'Employees with long term illnesses or disabilities in the UK social services workforce', *Disability and Society*, **18**(1), pp.51–70.
- O'Connell, C. (2003) *Taking Equal Opportunities Seriously: The Extension of Positive Duties to Promote Equality*, London: Equality and Diversity Forum.
- Owen, H. & Pritchard, J. (1993) *Good Practice in Child Protection. A Manual for Professionals*, London: Jessica Kingsley.
- RADAR (2007) *Case Study Examples of Disability Equality Duty Best Practice*, London: RADAR.
- Ruebain, D., Honnigmann, J., Mountfield, H. & Parker, C. (2006) *Review of Legislation, Regulations and Statutory Guidance within Professional Occupations*, London: DRC.
- Sapey, B., Turner, R. & Orton, S. (eds.) (2004) *Access to Practice: Overcoming the Barriers to Practice Learning for Disabled Social Work Students*, Southampton: SWAPIts.
- Scottish Executive (2002) *Regulation of Care (Requirements as to Care Services) (Scotland) Regulations 2002*, Scottish Statutory Instrument 2002, No. 114, Edinburgh: Scottish Executive.

- Scottish Executive (2005) *National Strategy for the Development of the Social Service Workforce in Scotland. A Plan for Action 2005 – 2010*, Edinburgh: Scottish Executive.
- Siepel, M.M.O. (1994) 'Disability: an emerging global challenge', *International Social Work*, **37**(2), pp.165–78.
- Sin, C.H. (2007a) 'Why fitness standards are vague and disabling', *Professional Social Work*, September, pp.16–7.
- Sin, C.H. (2007b) 'Embracing equality and diversity – from tackling discrimination to promoting equality', Disability Equality and Human Rights seminar, 11 July, University of Warwick, unpublished.
- Sin, C.H. & Fong, J. (2007a) 'Are caring professions restricting employment of disabled people?', *Journal of Integrated Care*, **15**(6), pp.44–8.
- Sin, C.H. & Fong, J. (2007b) 'The interpretation and implementation of regulatory fitness requirements', *British Journal of Nursing*, **16**(22), pp.1423–27.
- Sin, C.H., Kreel, M., Johnston, C., Thomas, A. & Fong, J. (2006) *Background to the Disability Rights Commission's Formal Investigation into Fitness Standards in Social Work, Nursing and Teaching Professions*, London: DRC.
- Sin, C.H., Fong, J., Momin, A. & Forbes, V. (2007a) *The Disability Rights Commission's Formal Investigation into Fitness Standards in Social Work, Nursing and Teaching Professions: Report on the Call for Evidence*, London: DRC.
- Sin, C.H., Fong, J., Momin, A. & Forbes, V. (2007b) 'Fit for purpose? Guidelines for implementing fitness standards in practice in teaching, nursing and social work', *The Skill Journal*, **88**, June, pp.6–11.
- Stanley, N., Ridley, J., Manthorpe, J., Harris, J. & Hurst, A. (2007) *Disclosing Disability: Disabled Students and Practitioners in Social Work, Nursing and Teaching. A Research Study to Inform the Disability Rights Commission's Formal Investigation into Fitness Standards*, London: University of Central Lancashire and the Social Care Workforce Research Unit, King's College, London for the DRC.
- Tanner, D. (1998) 'The jeopardy of risk', *Practice*, **10**(1), pp.15–28.
- Thompson, N. (2006) *Anti-discriminatory Practice*, London: Palgrave Macmillan.
- Titterton, M. (2004) *Risk and Risk Taking in Health and Social Welfare*, London: Jessica Kingsley.
- Wilson, A. & Beresford, P. (2000) "'Anti-oppressive practice": Emancipation or appropriation?', *British Journal of Social Work*, **30**(5), pp.553–73.
- Wray, J., Gibson, H. & Aspland, J. (2007) *Research into Assessments and Decisions Relating to 'Fitness' in Training, Qualifying and Working Within Teaching, Nursing and Social Work*, London: University of Hull for the DRC.

Notes on Contributors

The authors were at the Disability Rights Commission when the work for this paper was conducted. The first author was Head of Information and Research, while the second and third authors were Research Officers. The Disability Rights Commission ceased to exist from 1 October 2007, with its functions absorbed into the new Equality and Human Rights Commission that also has responsibilities for human rights and the other 'equality strands' of race, gender, sexual orientation, age, faith and religion.

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Appendix 1: Key evidence-gathering exercises for the Formal Investigation

Evidence strand	Objective	Data and analysis
Regulatory review	Explores the interaction of the statutory/regulatory frameworks with the Disability Discrimination Act (DDA).	<p>Conducted by Ruebain <i>et al.</i> (2006).</p> <p>Relevant legislation, regulations and statutory guidance covering higher education, registration and employment across England, Scotland and Wales.</p> <p>Templates used in the document review to help draw out relevant themes systematically.</p>
Call for evidence from key organisations	Solicits opinions from key stakeholder organisations, including government departments, regulatory bodies, disability organisations, trade unions, and professional bodies about the extent to which the regulatory framework may or may not have an impact on disabled people; and the reasons for this.	<p>A structured instrument soliciting relevant information sent electronically to Chief Executives or Directors of identified organisations.</p> <p>40 organisations responded.</p> <p>Analysis of written-in responses and submitted documents by DRC, undertaken using NVivo 7 via thematic content analysis. Reported in full by Sin <i>et al.</i> (2007a).</p>
Research into decision-making around fitness issues in higher education institutions	Investigates formal and informal decision-making around fitness within higher education institutions.	<p>Conducted by Wray <i>et al.</i> (2007).</p> <p>A two-part research instrument comprising a questionnaire section and a case study section was used.</p> <p>A stratified random sample was generated, and weighted by profession and country. 39 HEIs responded, representing a 39% response rate.</p> <p>Quantitative data analysed using SPSS v14, and qualitative data managed and analysed using NVivo 7. Thematic content analysis conducted on qualitative data.</p>
Research into decision-making around fitness issues in employment	Investigates formal and informal decision-making around fitness within employment context.	<p>Telephone survey of employers conducted by a market research company, Data Captain Ltd.</p> <p>A stratified random sample (weighted by profession and country) drawn from a sampling frame of commercial database of employers in the three professions.</p> <p>69 employers were interviewed, representing a 12.7% response rate. The survey instrument was based on the questionnaire designed by Wray <i>et al.</i> (2007), using the same broad themes.</p> <p>Data were analysed by DRC, using SPSS v14. Reported in full by Fong <i>et al.</i> (2007).</p>

Evidence strand	Objective	Data and analysis
<p>Research into disabled people's disclosure of information about their impairments or health conditions</p>	<p>Investigates the attitudes of disabled students and professionals towards disclosing disability, and identifies conditions that would encourage disclosure.</p>	<p>Conducted by Stanley <i>et al.</i> (2007).</p> <p>A qualitative methodology involving purposive sampling was used to capture the experiences and perceptions of disabled students and professionals.</p> <p>60 qualitative interviews conducted (mostly face-to-face with a few conducted over the telephone and some written accounts submitted). Sample included equal numbers from the three professions, balanced representation of students and practitioners and sufficient representation of the professions in England, Scotland and Wales.</p> <p>Data managed and analysed using NVivo 7, via thematic content analysis.</p>
<p>Inquiry Panel to discuss evidence with influential organisations.</p>	<p>Highlights and probes key issues, and tests emerging ideas for recommendations with key stakeholders.</p>	<p>An Inquiry Panel was convened and chaired by an independent barrister.</p> <p>Panel members included those with expertise in the professions covered by the GFI; disability issues; occupational health; higher education; and regulatory contexts in England, Scotland and Wales.</p> <p>23 witness sessions convened, involving more than 50 key organisations.</p> <p>All oral evidence transcribed and broad themes identified.</p>

Care management arrangements for people with physical and sensory disabilities: results of a national study

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Abstract

Care management has been an important component of the government's community care policy yet little is known about its implementation in services for people with physical and sensory disabilities. The study sought to fill this information gap by reporting a national survey of care management arrangements for these users around a previously devised framework. Marked variations were found in many aspects of care management arrangements, along with a lack of a differentiated approach and limited authority of care managers to allocate services responsively. The findings also suggest that some aspects of care management arrangements are less advanced in services for this user group than for people with learning disabilities. These results are discussed in the context of relevant policy initiatives and literature. Further evaluation studies on care management to inform future decision-making are indicated by this research. The limitations of the study are also acknowledged.

Keywords: Care management, physical and sensory disabilities, social care, social services

Introduction

The individualisation of support for people with physical and sensory disabilities has achieved greater prominence in recent policy, with a concern to expand direct payments and new initiatives to develop individual budgets to increase choice and the range of support available (Cm 6499, 2005; Cm 6737, 2006). Since the inception of the community care reforms of the 1990s, the assessment of need and planning of social care support has increasingly been delivered through care management arrangements (Cm 849, 1989; Cm 4169, 1998). Nevertheless, despite its importance, surprisingly limited information is available on care management arrangements in services for people with physical and sensory disabilities. Much of the available information is found in government inspection reports which describe the services available for users with specific needs rather than a more global review of

assessment and care management arrangements. These reports include an initial special report of the implementation of community care for younger people with physical and sensory disabilities (SSI/NHSME, 1993); and a number of inspections of services for people with multiple impairments (SSI, 1993), disabled young adults and their carers (SSI, 1995), physically disabled people (SSI, 1996), deaf and hard of hearing people (SSI, 1997), and adults who are visually impaired or blind (SSI, 1998). The inspection of independent living arrangements for younger disabled people (SSI, 2000) and the performance of social care services for physically and sensory disabled people (SSI, 2003) provide more recent information on service development. In general, the inspections revealed a large degree of variation in care management practice among local authorities. These included differences in approaches to assessment both in terms of the levels of assessment and the assessors

(SSI, 1995 & 1996); the extent to which care plans addressed the needs of carers; the range of agencies providing support (SSI, 1996) and the specification of intended outcomes (SSI, 1993 & 2000); monitoring procedures; and the frequency of and agencies involved in reviews (SSI, 1993 & 2000). Additionally, the inspections found little evidence of strategic inter-agency work (SSI, 1996 & 2000) and particularly partnerships with NHS organisations (SSI *et al.*, 2004), and there was a lack of clarity about who 'managed' care packages (SSI, 1995 & 1996). Other findings included the shortage of skilled staff (SSI/NHSME, 1993; SSI, 2003) and confusion over the role of specialist practitioners such as occupational therapists (OTs) in the assessment and care management processes (SSI, 2000 & 2003). The latter was confirmed in a separate study (Mountain, 2000). Overall, the whole process was seen as lacking an holistic approach to the needs of users and carers (SSI, 2000 & 2003).

There are very few peer-reviewed empirical studies on the provision of co-ordinated care for people with physical and sensory disabilities. A recent quasi-systematic review of such studies on adult social care published 1990-2003 (data 1990-2001) identified only a small number of studies on care management arrangements for people with physical and sensory disabilities (Challis *et al.*, 2004). Furthermore, these tended to focus on access to assessment and are not always exclusive to services for people with physical and sensory disabilities (Rummery, 1997; Ellis *et al.*, 1999; Rummery *et al.*, 1999). As described above, although government inspection reports provided some valuable insight into care management arrangements in services for this particular user group, they are usually based on selective samples and none focused primarily on care management arrangements. Against this background, the aims of this paper are twofold. Firstly, it aims to provide a national picture of care management arrangements in services for

people with physical and sensory disabilities, using a framework devised to reflect the key dimensions and indicators of care management arrangements (Challis *et al.*, 1998a). Secondly, it reviews these findings in the context of care management arrangements for the three other principal adult user groups since this is the final report in the series (Weiner *et al.*, 2002; Venables *et al.*, 2005; Xie *et al.*, 2007).

Research methods

The survey

This paper is based on a postal survey of services for disabled adults in England, between the ages of 18 and 65 years, where physical disability and/or sensory impairment is the predominant disability (referred to as people with physical and sensory disabilities hereafter). It was designed to reflect current policy guidelines for this user group and complement an earlier survey of care management arrangements for all adult user groups (Challis *et al.*, 1998b). Questionnaires were sent to all English councils with social services responsibilities in 2003/4, and they were completed by officers with a lead responsibility for services for people with physical and sensory disabilities. Findings related to care management arrangements are reported in the present paper. They are presented sequentially along three key dimensions of care management: organisational arrangements, performance of the core tasks of care management, and the degree of differentiation within the process (Challis *et al.*, 1998a). These are summarised in Figure 1. The operational definitions of the indicators are given where appropriate.

Findings

Response rate by type of authority

One hundred and twenty completed questionnaires were returned by April 2004,

a response rate of 81%, as shown in Table 1. However, whilst over 90% of metropolitan and county councils responded to the physical and sensory disability survey, the figure for London boroughs was just under 60%.

Figure 1 Key Indicators of the implementation of care management

Care management attribute	Indicator variable
Organisational arrangements:	
Record of innovation	Care management before 1993 (including pilot schemes)
Purchaser/provider split	Date of introduction for domiciliary care
Level of authority to purchase	Lowest level for community based care packages
Performance of core tasks:	
Staff mix	Qualification and agency
Tiers of assessment	Number of levels for services for disabled adults
Reviews	Extent of arrangements for community based and residential care for disabled adults
Continuity	Across assessment and care management tasks for disabled adults
Role or process	Job title or organisational arrangements
Clinical or administrative	Acknowledgement (or not) of social work skills
Degree of differentiation:	
Specialism	Care management staff based in specialist disabled adult teams
Targeting	None, focused
Caseload size	Average active caseload size for disabled adults
Intensive care management	Small caseload, high needs service purchased or provided for disabled adults
Selective care management	Service provided to some, but not the majority of service users

Table 1 Response rate by social service local authority type

	Type of Local Authority				Total
	London boroughs	Metropolitan districts	Counties	New local authorities	
Total authorities	33	36	34	46	149
Number of respondents	19	33	31	37	120
Response rate (%)	58	92	91	80	81

Organisational arrangements

The indicator of organisational arrangements - the level of authority to purchase care packages - was operationalised as care managers' authority to allocate services, to reflect the extent of budgetary devolution to front line staff. As shown in Table 2, the percentage of respondents indicating that all elements of services could be allocated by such staff was small, 3% for both in-house and external services. However, nearly 60% of respondents indicated that care managers could commit no external services and nearly half stated that this was the case in respect of in-house services. Additionally, only a fifth of local authorities reported that care managers could allocate direct payments to implement a care package without consultation with a first line manager or other more senior person.

Performance of core tasks

Two types of information are reported in this section: who undertakes care management and the nature of care management in services for people with physical and sensory disabilities. In terms of staff mix, as shown in Table 3, almost all local authorities reported the potential involvement of both social services and health staff in undertaking assessments. However, further examination revealed that health staff were always involved in the assessment of people with physical and sensory disabilities in only one fifth of the local authorities: in the remainder, health staff were only sometimes involved. The involvement of housing, employment and education agencies in the assessment process was very limited. Nearly a quarter of respondents (24%) reported that they did not involve colleagues from education or employment in the assessment of adults with physical and sensory disabilities. It is also relevant to note that only 13% of the respondents reported having NHS staff

working as care managers, whilst 57% reported having Social Services Department (SSD) employed OTs acting as care managers.

With regard to the nature of care management arrangements, as Table 3 indicates, nearly two thirds (64%) of the respondents considered care management to be a *specific job undertaken by designated members of staff called care managers*, and three quarters (75%) described it as *a set of standardised procedures and protocols applied for all service users*. Just over two thirds (68%) thought it *necessarily encompassed a social work style and approach* in services for people with physical and sensory disabilities.

Degree of differentiation

This dimension is defined as the extent to which care management arrangements vary according to the needs of the individuals who receive them, and three of the five indicators are measured in the present survey: the degree of specialisation by team; the extent of intensive care management arrangements; and indicators of selective care management.

Table 2 Organisational arrangements

Indicator of care management system	% of authorities
Authority to purchase	
<i>Authority of basic grade staff in disabled adult services to allocate directly provided services</i>	
All services	3
Some services	41
1 or 2 services	9
None	48
<i>Authority of basic grade staff in disabled adult services to allocate external services</i>	
All services	3
Some services	31
1 or 2 services	8
None	59
<i>Authority of basic grade staff in disabled adult services to allocate direct payments</i>	
Yes	20
No	80

Table 3 Performance of core tasks

System indicator	% of authorities		
Staff mix			
<i>Agencies involved in assessment</i>			
	Always	Sometimes	Never
SSD	88	12	0
Health	20	79	1
Housing	1	89	10
Education	2	74	24
Employment	1	75	24
<i>NHS care managers in disabled adult services</i>			13
<i>Occupational therapists in SSD acting as care managers</i>			57
Role or process			
Care management in disabled adult services is a specific job undertaken by designated members of staff called care managers			64
A set of standardized procedures and protocols applied for all service users			75
Clinical or administrative approach			
Care management in disabled adult services necessarily encompasses a social work style and approach			68

Table 4 Degree of differentiation of care management approach

Attribute of care management approach	% of authorities
Specialist teams for services to disabled adults	
<i>Primary location of care managers or those undertaking the equivalent role</i>	
Specialist disability team in SSD	74
Hospital	50
Generic adult services team in SSD	41
Multi-agency community disability team	20
Primary care	11
Day services	6
<i>Assessment and care management for people with dual sensory impairments</i>	
By a specialist team for adults with these sensory impairments	63
By specialist staff within a physical disability team	24
By an agent offering a specialist service (e.g. a voluntary organization)	24
By a generic team	2
Intensive care management in disabled adult services	
A complex co-ordinating activity such that caseloads are small	20
People with complex needs receive intensive help different from other users	37
Selective care management in disabled adult services	
<i>Description of care management arrangements</i>	
Care management provided to a limited number of service users	11
Care management provided to a majority of service users	73

Specialisation is indicated by the primary location of care managers or their equivalent for people with physical and sensory disabilities. As Table 4 shows, nearly three quarters (74%) of respondents reported that care managers or their equivalent were based in specialist disability teams within the local authority, half reported that they were based in hospital, two fifths (41%) in generic adult teams, and one fifth in multi-agency community disability teams. Other locations included primary care and day services, at 11% and 6% respectively. The degree of specialisation is further illustrated by local authorities' care management arrangements for people with dual sensory impairments, whose needs are, by definition, complex. Nearly two thirds (63%) of the respondents reported that assessment and care management for this particular group of people was provided by a specialist team for people with these

sensory impairments and about a quarter (24%) by staff within a physical disability team. This service was also reported as provided by an agent offering a specialist service by about a quarter (24%) of respondents.

Intensive care management was defined as a specialist care management service working exclusively with people with high needs undertaken by staff who carry small caseloads. In the present study, one fifth of authorities considered care management as *an activity involving the co-ordination and delivery and monitoring of services to a degree of complexity, such that caseloads are, as a consequence, small*. However, 37% of the respondents reported that the statement *an activity by which people with complex needs receive intensive help*

different in nature and scope to other service users described their departments' care management arrangements. A more precise indicator was not available.

Selective care management, referring to the use of assessment and care management arrangements for only a proportion of service users, was measured by whether the respondents perceived care management as a response provided to the majority of service users or only to a limited number of users. Nearly three quarters (73%) of the respondents reported that their departments' care management arrangements would be described as *a response provided to the majority of service users*. In contrast, only 11% selected *a response provided only to a limited number of service users*. Several respondents (20%) did not specify this aspect of care management arrangements.

Discussion

The present study has provided information on some of the indicators for the three key dimensions of the care management arrangements framework. Data reported in an earlier work is available in respect of levels of assessment and reviews for the core tasks dimension, and caseload size for degree of differentiation for this user group (Challis *et al.*, 1998b & 1999). In this section the findings will be discussed in relation to findings from other studies concerning services for people with physical and/or sensory disabilities and evidence from the series of PSSRU studies of care management relating to other adult user groups. Overall, the state of care management arrangements for people with physical disability is considered and areas for further investigation highlighted. First however, the limitations of the study are discussed.

Some aspects of care management such as the content of care plans were not investigated in the present study, since these questions are deemed unsuitable for a postal

survey and would require more in-depth investigation. Furthermore, some findings relevant to care management, not included within the current framework, were not reported, such as management information and joint commissioning. Finally, the care management analytic framework (Challis *et al.*, 1998a) was only partially populated by the present study and information on some indicators was only available from an earlier work. It is also important to note that work is currently underway to amend and update the framework so as to reflect changes in both policy and service context. Notwithstanding these caveats, the use of the framework permits comparison with findings relating to care management arrangements for other user groups.

Service configuration

The present study indicated a reasonably high degree of specialisation in services for people with physical disabilities. This is consistent with a survey conducted at roughly the same time (SSI, 2003), and suggests that there has been an increase in the proportion of SSDs having specialist disability teams in recent years (Challis *et al.*, 1999; SSI, 2000). Despite this, a significant number of local authorities reported having care managers based in generic adult teams and this proportion is much higher than that in learning disability and mental health services (Venables *et al.*, 2005; Xie *et al.*, 2007), reflecting a longstanding concern about specialisation for this user group (SSI/NHSME, 1993; SSI, 2000 & 2003). Although the benefits of multi-disciplinary joint agency teams for people with physical and sensory disabilities are well-documented (SSI, 1993, 1996; Bent *et al.*, 2002; Harris *et al.*, 2005), the proportion of local authorities that reported having such teams as the primary location of care managers is small and again is much lower than that in mental health and learning disability services (Venables *et al.*, 2005; Xie *et al.*, 2007) where multidisciplinary teams have been in

existence for some time (DHSS, 1978; SSI, 2000). Earlier data makes much the same point in older people's services (Weiner *et al.*, 2002) although it appears that specialist teams in older people's services have developed subsequently (Challis *et al.*, 2007).

Local authorities are required to "ensure that when an assessment of people with dual sensory impairments is required or requested, it is carried out by a specifically trained person/team" (DH, 2001a). The present study revealed that assessment and care management for these people are provided in clearly different ways and that agencies other than SSDs still play a significant role. This is consistent with previous findings on services for people with sensory impairments (SSI, 1993, 1997 & 1998), although thus far there is insufficient evidence to suggest that any one of these approaches was superior (SSI, 1997).

Whilst specialist knowledge and skills are essential for good quality services for people with sensory impairments, there have been concerns about the marginalisation and lack of communication of these specialist staff with other colleagues within local authorities, and there have been calls for such specialist teams to be part of more general care management arrangements (SSI, 1993, 1997 & 1998). The present study indicates that a pattern of separate service provision remains prevalent in assessment and care management arrangements for people with dual sensory impairments.

Since occupational therapy services can contribute significantly to helping people achieve greater mobility and independence it is important to clarify the position of OTs in relation to the care management process (Mountain, 2000). Although over half of the authorities reported having OTs as care managers in the present study, other studies indicate that the proportion of occupational therapy services operating a dedicated care

management function was very small (4%) and that authorities varied significantly in how they deployed and used OTs (Mountain, 2000; SSI, 2000). These results indicate that a strategic shift of occupational therapy services towards a care management function has not been uniform. It has been suggested that such a shift and a more holistic vision of rehabilitation and needs could be beneficial for both service users and the OT workforce (Mountain, 2000; SSI, 2003).

In services for people with physical and sensory disabilities, the proportion of local authorities reporting having NHS staff as care managers is much lower than that in learning disability services (and lower than that in mental health and older-people's services in 1998) (Weiner *et al.*, 2002; Venables *et al.*, 2005; Xie *et al.*, 2007). This is perhaps an indication of the progress of partnership working and integration with other agencies in general and the NHS in particular at both agency and service level. Previous studies identified little evidence of strategic inter-agency work and integration in the care management processes for people with physical and sensory disabilities (SSI, 1996 & 2000). Furthermore, it has been noted that significantly less progress has been made in using Health Act Flexibilities for services for disabled people than for services for other adult groups (SSI, 2003), and that much fewer physical and sensory disability services have established formal partnerships with NHS organisations than have learning disability services (SSI *et al.*, 2004). Again this may relate to the longer history of multi-disciplinary teams in services for some user groups which provided a platform for the early development of multi-disciplinary care management (Cmnd 6233, 1975; DHSS, 1978; Cambridge, 1992), and recent national policy frameworks which emphasise partnership working (DH, 1999 & 2001b; Cm 5086, 2001).

Care management practice

Integrated assessment appropriate to the level of need has been identified as a means to achieve effective service delivery for a whole range of services (SSI/SWSG, 1991a & b; DH, 2002a). Initial guidance at the inception of the community care reforms required local authorities to move away from separate assessment procedures for different services to an integrated assessment system that offers a graded response according to the type and level of need, and allowed six levels of assessment (SSI/SWSG, 1991a & b). For people with physical and sensory disabilities, an earlier study revealed that different levels were in operation, though the pattern of variation was similar to that for other adult user groups (Challis *et al.*, 1998b). More substantial concerns emerge in a review of the evidence relating to assessment processes, both in terms of content and documentation for people with physical and sensory disabilities (SSI, 1995, 1996 & 2000). The present study confirms the evidence of a lack of inclusion of relevant agencies in the assessment processes for this user group (SSI, 1993, 1996, 2000 & 2003), contrary to policy guidance (DH, 2002a). Interestingly, the involvement of other agencies in the assessment process is less obvious in services for people with physical and sensory disabilities than in learning disability, older people's or mental health services (SSI, 2000; Weiner *et al.*, 2002; Venables *et al.*, 2005; Xie *et al.*, 2007). There have been attempts to enhance approaches to assessment for other user groups through initiatives such as the Single Assessment Process (SAP) (DH, 2002b), Person-Centred-Planning (PCP) (Cm 5086, 2001) and the Care Programme Approach (CPA) (DH, 1999), but no such initiative is evident in services for people with physical and sensory disabilities with the possible exception of those with dual sensory impairments (DH, 2001a). However, the development of the Common Assessment Framework offers an opportunity for this

since it refers to all adult service user groups (Cm 6737, 2006, para. 5.26).

The study suggests that there is only a limited degree of differentiation (as previously defined) within the care management process in services for this user group. In general, the average active caseload size in services for people with physical and sensory disabilities was similar to that in older people's services, but larger than that in learning disability and mental health services (Challis *et al.*, 1998b). Intensive care management was very rare for people with physical disabilities and almost non-existent for people with sensory impairments back in 1997, and this lack of intensive and selective care management is common to all adult user groups (Challis *et al.*, 1999; Weiner *et al.*, 2002; Venables *et al.*, 2005). Targeting, within care management, is defined as allocation of cases with different needs to different levels of staff, different levels of assessment for different types or cost of services or the use of intensive care management (Weiner *et al.*, 2002). However, the degree to which staff and resources were targeted according to user need in services for people with physical and sensory disabilities was unclear. There is also little evidence concerning this aspect of care management arrangements for adults with a physical and sensory disability in the literature (Challis *et al.*, 2004). Nonetheless, in the absence of priority statements and mechanisms for disabled people with complex needs (SSI, 1993 & 1997), it is difficult to ensure the targeting of scarce resources on those likely to be most in need. However, for those experiencing frequent hospital admissions the National Service Framework for People with Long Term conditions may address this concern, with a case management service provided by primary care based staff (DH, 2005a & b).

Tailoring services to needs

The early care management demonstration projects (Challis & Davies, 1986; Challis *et al.*, 1995, 2002a & b) indicated that individualised and person-centred packages of care were fostered by devolved budgets which permitted care managers to purchase services responsive to individual need and choice. Despite this being a key feature of responsive care management, the present study reveals that the authority of care managers to create such customised packages for people with physical and sensory disabilities was limited, confirming previous findings (SSI, 1995 & 1996). Care managers' authority to allocate direct payments also appears very limited in services for this user group. Although most users of direct payments are people with physical and sensory disabilities, the take up was still quite low, especially for people with sensory disabilities (SSI, 2003; CSCI 2004; SSI *et al.*, 2004; Riddell *et al.*, 2005). Conceivably, an increase in care managers' authority to allocate direct payments through changes in organisational arrangements and an increase in their knowledge of direct payments through training, would enhance the take-up rate of direct payments (SSI, 2000 & 2003; CSCI, 2004).

Moreover, it is possible that the emergence of individual budgets as a tool to increase the flexibility and range of support available may contribute to greater responsiveness within care management arrangements, and provide both an environment for its further development (Cm 6499, 2005; Cm 6737, 2006; Glendinning *et al.*, 2007; SCIE, 2007) and a framework whereby some of the gains of early care management research may be realised (Challis, 2003). Indeed this could provide an impetus for services for people with physical and sensory disabilities to make considerable progress.

Progress and prospects

This study has attempted to provide an overall picture of care management arrangements in services for people with physical and sensory disabilities in England, with information on aspects of care management that have never been systematically investigated before. The findings reveal marked variations in care management arrangements in services for this user group. Local authorities differed in almost all indicators along the three dimensions of care management arrangements identified in Figure 1, with the exception of an almost universal absence of both intensive and selective care management, and evidence of the limited authority of care managers to develop services responsive to individual needs. These findings are consistent with other studies concerning this user group (SSI, 1996 & 2000), and the pattern of variation of care management arrangements is broadly similar to that in services for other user groups (Weiner *et al.*, 2002; Venables *et al.*, 2005; Xie *et al.*, 2007). These variations may have at least partly resulted from the lack of specificity in the guidance on care management which permitted much latitude of interpretation and encouraged local authorities to test a variety of arrangements (SSI/SWSG, 1991a & b; Welch, 1998).

Overall, the findings support the view that care management arrangements in services for people with physical and sensory disabilities lag behind services for people with learning disabilities surveyed at the same time (Xie *et al.*, 2007). Indeed, available evidence tends to suggest that services for people with physical and sensory disabilities are less advanced than services for other user groups, both in terms of care management arrangements and many other aspects of service development (Beardshaw, 1988; SSI, 2000 & 2003; Challis *et al.*, 2005a & b). Possible reasons for this state of affairs include the low

priority given to this user group in the implementation of care management in the 1990s, and the lack of a national policy framework driving developments in physical and sensory disability services in recent years (SSI/NHSME, 1993; SSI, 1996, 2000 & 2003).

Now, more than a decade after the implementation of the community care reforms, further studies on the evaluation of different approaches to care management and care management in general are needed, to address concerns over the effectiveness of different approaches to care management, and to provide evidence for future policy development (Marshall *et al.*, 1995; Baldwin, 2000; Lloyd, 2000; Challis, 2003; Greco & Sloper, 2004). This is especially true for services for people with physical and sensory disabilities in that early UK care management experience was drawn largely from older people's services, and had not been systematically evaluated in disabled adult services. Interestingly, a recent care management study with a focus on outcomes has achieved some promising early results for people with physical and sensory disabilities (Harris *et al.*, 2005). Future studies will need to take into account the potential impact of recent policy initiatives issued after this study was conducted, particularly individual budgets, the introduction of self-assessment techniques and new approaches to care management (Cm 6737, 2006).

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References

- Baldwin, M. (2000) *Care Management and Community Care: Social Work Discretion and the Construction of Policy*, Aldershot: Ashgate.
- Beardshaw, V. (1988) *Last on the List: Community Services for People with Physical Disabilities*, London: King's Fund Institute.
- Bent, N., Tennant, A., Swift, T. & Chamberlain, A. (2002) 'Does type of provision affect the participation of physically disabled young adults?', *Clinical Rehabilitation*, **16**(1), p.115.
- Cambridge, P. (1992) 'Case management in community services: organizational responses', *British Journal of Social Work*, **22**(5), pp.495-517.
- Challis, D. (2003) 'Achieving Co-ordinated and Integrated Care among Long Term Care Services: the Role of Care Management', in Brodsky, J., Habib, J. & Hirschfeld, M. (eds.), *Key Policy Issues in Long Term Care*, Geneva: World Health Organisation, pp.139-90.
- Challis, D. & Davies, B. (1986) *Case Management in Community Care*, Aldershot: Gower.
- Challis, D., Darton, R., Johnson, L., Stone, M. & Traske, K. (1995) *Care Management and Health Care of Older People*, Aldershot: Ashgate.
- Challis, D., Darton, R., Hughes, J., Huxley, P. & Stewart, K. (1998a) 'Emerging models of care management for older people and those with mental health problems in the United Kingdom', *Journal of Case Management*, **7**(4), pp.153-60.
- Challis, D., Darton, R., Hughes, J., Stewart, K. & Weiner, K. (1998b) *Care Management Study: Report on National Data*, London: Department of Health.
- Challis, D., Darton, R., Hughes, J., Stewart, K. & Weiner, K. (1999) *Mapping and Evaluation of Care Management Arrangements for Older People and Those with Mental Health Problems: An Overview of Care Management Arrangements*, report submitted to the Department of Health, PSSRU, University of Manchester, Discussion Paper 1519/M009.
- Challis, D., Chesterman, R., Lockett, R., Stewart, K. & Chessum, R. (2002a) *Care Management in Social and Primary Health Care*, Aldershot: Ashgate.

- Challis, D., von Abendorff, R., Brown, P., Chesterman, J. & Hughes, J. (2002b) 'Care management, dementia care and specialist mental health services: an evaluation', *International Journal of Geriatric Psychiatry*, **17**(4), pp.315-25.
- Challis, D., Xie, C., Hughes, J., Jacobs, S., Reilly, S. & Stewart, K. (2004) *Social Care Services at the Beginning of the 21st Century - Findings*, report to the Department of Health, PSSRU, University of Manchester, Discussion Paper M098.
- Challis, D., Xie, C., Hughes, J., Jacobs, S., Reilly, S. & Stewart, K. (2005a) *Social Care Services at the Beginning of the 21st Century - Executive Summary*, PSSRU, University of Manchester, Discussion Paper M104, accessed 07/11/2007 at http://www.pssru.ac.uk/pdf/MCpdfs/EXECUTIVE_SUMMARY.pdf.
- Challis, D., Xie, C., Hughes, J., Jacobs, S., Reilly, S. & Stewart, K. (2005b) *Social Care Services at the Beginning of the 21st Century - Summary and Conclusions*, report to the Department of Health, PSSRU, University of Manchester, Discussion Paper M105.
- Challis, D., Hughes, J., Jacobs, S., Stewart, K. & Weiner, K. (2007) 'Are different forms of care management for older people in England associated with variations in case-mix, service use and care managers' use of time?', *Ageing and Society*, **27**(1), pp.25-48.
- Cm 849 (1989) *Caring for People*, London: HMSO.
- Cm 4169 (1998) *Modernising Social Services. Promoting Independence, Improving Protection, Raising Standards*, London: Stationery Office.
- Cm 5086 (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London: The Stationery Office.
- Cm 6499 (2005) *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England*, London: Department of Health.
- Cm 6737 (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services*, London: Department of Health.
- Cmnd 6233 (1975) *Better Services for the Mentally Ill*, London: HMSO.
- Commission for Social Care Inspection (2004) *Direct Payments: What Are the Barriers?* London: CSCI.
- Department of Health (1999) *Effective Care Co-ordination in Mental Health Services: Modernising the Care Programme Approach. A Policy Booklet*, London: Department of Health.
- Department of Health (2001a) *Social Care for Deafblind Children and Adults*, LAC (2001)8, London: Department of Health.
- Department of Health (2001b) *National Service Framework for Older People*, London: Department of Health.
- Department of Health (2002a) *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care*, LAC (2002)13, London: Department of Health.
- Department of Health (2002b) *Guidance on the Single Assessment Process for Older People*, HSC2002/001; LAC (2002)1, London: Department of Health.
- Department of Health (2005a) *The National Service Framework for Long Term Conditions*, London: Department of Health.
- Department of Health (2005b) *Supporting People with Long Term Conditions: An NHS and Social Care Model to Support Local Innovation and Integration*, London: Department of Health.
- Department of Health and Social Security (1978) *Development Team for the Mentally Handicapped, First Report: 1976-77*, London: HMSO.
- Ellis, K., Davis, A. & Rummery, K. (1999) 'Needs assessment, street-level bureaucracy and the new community care', *Social Policy and Administration*, **33**(3), pp.262-80.
- Glendinning, C., Challis, D., Fernández, J., Jones, K., Knapp, M., Manthorpe, J., Netten, A., Stevens, M. & Wilberforce, M. (2007) 'Evaluating the individual budget pilot projects', *Journal of Care Services Management*, **1**(2), pp.123-8.
- Greco, V. & Sloper, P. (2004) 'Care co-ordination and key worker schemes for disabled children: results of a UK-wide survey', *Child Care, Health and Development*, **30**(1), pp.13-20.
- Harris, J., Foster, M., Jackson, K. & Morgan, H. (2005) *Outcomes for Disabled Service Users*, Department of Health Final Report, SPRU, University of York.

- Lloyd, M. (2000) 'Where has all the care management gone? The challenge of Parkinson's Disease to the health and social care interface', *British Journal of Social Work*, **30**(6), pp.737-54.
- Marshall, M., Lockwood, A. & Gath, D. (1995) 'Social services case-management for long-term disorders: a randomised controlled trial', *The Lancet*, **345**(Feb. 18), pp.409-12.
- Mountain, G. (2000) *Occupational Therapy in Social Services Departments: A Review of the Literature*, London: College of Occupational Therapists, Centre for Evidence-Based Social Services, University of Exeter.
- Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M. & Mercer, G. (2005) 'The development of Direct Payments in the UK: implications for social justice', *Social Policy and Society*, **4**(1), pp.75-85.
- Rummery, K. (1997) 'Accessing assessment: the perspectives of practitioners, disabled people and carers', *Social Services Research*, **2**(1), pp.11-21.
- Rummery, K., Ellis, K. & Davis, A. (1999) 'Negotiating access to community care assessments: perspectives of front-line workers, people with a disability and carers', *Health and Social Care in the Community*, **7**(4), pp.296-300.
- Social Care Institute for Excellence (2007) *Choice, Control and Individual Budgets: Emerging Themes*, Research Briefing 20, London: SCIE.
- Social Services Inspectorate (1993) "Whose Life Is It Anyway?" *A Report of an Inspection of Services for People with Multiple Impairments*, London: Department of Health.
- Social Services Inspectorate (1995) *Searching for Service: An Inspection of Social Services for Disabled Young Adults and Their Carers*, London: Department of Health.
- Social Services Inspectorate (1996) *Progressing Services with Physically Disabled People. Report on Inspections of Community Services for Physically Disabled People*, London: Department of Health.
- Social Services Inspectorate (1997) *A Service on the Edge: Inspection of Services for Deaf and Hard of Hearing People*, London: Department of Health.
- Social Services Inspectorate (1998) *A Sharper Focus: Inspection of Services for Adults Who Are Visually Impaired or Blind*, London: Department of Health.
- Social Services Inspectorate (2000) *New Directions for Independent Living. Inspection of Independent Living Arrangements for Younger Disabled People*, London: Department of Health.
- Social Services Inspectorate (2003) *Independence Matters: An Overview of the Performance of Social Care Services for Physically and Sensory Disabled People*, London: Department of Health.
- Social Services Inspectorate, Joint Reviews of Social Services & National Care Standards Commission (2004) *All Our Lives: Social Care in England - 2002-2003*, London: Department of Health.
- SSI/NHSME (1993) *Implementing Community Care for Younger People with Physical and Sensory Disabilities: Report and Findings of the SSI/NHSME Special Report*, London: Department of Health.
- Social Services Inspectorate and Social Work Services Group (1991a) *Care Management and Assessment: Managers' Guide*, London: HMSO.
- Social Services Inspectorate and Social Work Services Group (1991b) *Care Management and Assessment: Practitioners' Guide*, London: HMSO.
- Venables, D., Stewart, K., Hughes, J., Weiner, K., Darton, R. & Challis, D. (2005) 'Variations in care management arrangements for people with mental health problems in England', *Care Management Journals*, **6**(3), pp.131-8.
- Weiner, K., Stewart, K., Hughes, J., Challis, D. & Darton, R. (2002) 'Care management arrangements for older people in England: key areas of variation in a national study', *Ageing & Society*, **22**(4), pp.419-39.
- Welch, B. (1998) 'Care Management and Community Care: Current Issues', in Challis, D., Darton, R. & Stewart, K. (eds.), *Community Care, Secondary Health Care and Care Management*, Ashgate: Aldershot, pp.11-24.
- Xie, C., Hughes, J., Challis, D., Stewart, K. & Cambridge, P. (2007) 'Care management arrangements in learning disability services: results of a national study', *Journal of Applied Research in Intellectual Disabilities*, Online Early published 02 Aug. 2007, doi: 10.1111/j.1468-3148.2007.00391.x.

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Implementing the reimbursement scheme - views of health and social care staff in six high performing sites

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Abstract

The Community Care (Delayed Discharges) Act 2003 announced a new reimbursement scheme which was intended to accelerate the downward trend in rates of delayed discharges and strengthen joint working between acute health trusts and social services. Under the new scheme hospitals and social services were to agree new inter-agency discharge planning protocols and communication systems, and to operate new legal notification systems that required hospitals to give social services formal notification at least 3 days in advance of a patient's planned discharge. Agencies were required to agree the numbers of delays each agency was responsible for each week, and acute trusts could charge local authorities for any delays for which they were responsible. Critics warned that the scheme was unsuited to the task, and that its implementation might put partnership working and patient care at risk.

This paper explores health and social care staff views on the early working of the reimbursement scheme taken from a broader study of the factors associated with low rates of delays in six sites where performance (in terms of rates of delayed discharge) was exceptionally good. Forty-three qualitative interviews were undertaken between June 2004 and March 2005 with a range of health and social care professionals responsible for, or involved in, discharge arrangements in the six sites.

For the majority of staff, the scheme has largely supported joint working; it provided substantial new funding to social services departments for joint commissioning, it has required joint implementation of new interagency notification systems, and close monitoring and interagency communication around delays. Whilst those working with new notification systems have experienced some difficulties with reaching a shared understanding of what is required, the notification system appears to have supported clear and timely communication around discharge between ward and social services staff. Impacts on patients were not clear cut, but there were concerns from some social services staff that, as a result of reimbursement, there was greater likelihood of 'hurried' discharges.

This paper offers important insights into the early working of the scheme in sites where agencies were already performing well in terms of delayed discharges. It should be of interest to those involved in implementing the reimbursement scheme or with a role in discharge arrangements.

Keywords: Delayed hospital discharge, implementing reimbursement

Introduction

This paper explores the experiences of health and social care staff with regard to the implementation and early working of the reimbursement scheme in sites where the rates of delays are already low. The findings presented in this paper are based on re-analysis of qualitative data obtained from a broader study which aimed to elicit the essence of 'what works' in sites that had already addressed delayed discharges in order that this could be shared with sites still struggling with delays (see Baumann *et al.*, 2007).

Background

Delayed discharges from hospital have posed a problem for the welfare state since its inception (Schimmel, 1964) and have provided a regularly recurring topic in the health services literature (Taraborelli, 1998). Whilst certain groups of patients such as older people, those without informal carers, those who live alone, and those with complex medical needs are most at risk of delays (Victor *et al.*, 2000) it is widely acknowledged that delays are overwhelmingly a result of organisational issues including internal hospital factors, availability of community services, and interagency communication (Victor *et al.*, 2000; House of Commons Select Committee on Health, 2002; National Audit Office, 2003; Glasby, 2004; Scottish Executive, 2004). According to one author who has, arguably, delved deeper than any into the problem of delayed discharge (Glasby, 2004; Glasby & Littlechild, 2004) interagency delays are the result of a complex range of long-standing structural, cultural, policy, legal and funding issues that stand in the way of progress.

The National Audit Office (2003) and the House of Commons Select Committee on Health (2002) also offer an holistic approach to understanding the problem of delayed discharges, emphasising:

- **Insufficient capacity** in the health and social care system;
- **Internal health system inefficiencies** such as limited or inefficient advanced discharge planning; delays in making health assessments because of shortages in occupational therapists and physiotherapists; competing priorities for time; poor coordination and communication delays in preparation of discharge medicines and poor availability of transport services;
- **Inter-agency factors** such as a lack of clear multi-agency discharge protocols, poor quality interagency communication systems and slow progress with the implementation of single assessment arrangements.

A range of initiatives has been launched since 1997, which aim to address these long-standing problems and to tackle delayed discharge (Glasby & Littlechild, 2004; Baumann *et al.*, 2007). But, by 2002, although progress was being made, rates of delays had not reduced substantially, and the government announced its intention to accelerate progress through the introduction of a reimbursement scheme based on the Swedish system (DH, 2002).

The government claimed that the system of payment transfers or 'cross-charging' would reduce delays by encouraging greater responsiveness from social services - a claim which was based on the Swedish experience of implementing the scheme a decade previously (see Andersson & Karlberg, 2000). Initially, only limited information about the scheme was announced; the 'one-liner' which was, unfortunately, the basis for most of the subsequent commentary, was that local authorities would be required to make payments to acute trusts for each day where a delay in discharge is a result of their failure to assess or provide services. As Henwood (2004, p.4) noted, this was

“enormously controversial” because it appeared to attribute the responsibility for delays entirely to social services, at a time when there was increasing evidence that there was a complex range of national and local, and multi-agency causes of delays.

The House of Commons Select Committee on Health, in its inquiry into delayed discharges, suggested that reimbursement would be extremely complex to implement, unlikely to succeed in addressing the various causes of delays and risked undermining interagency relationships (HCSC, 2002). For the most part, commentators agreed (Henwood, 2004) and several feared that the scheme would, in addition, have a detrimental impact on patient care and outcomes (HCSC, 2002; Glasby, 2003; Moss, 2004; Rowland & Pollock, 2004; Wilkinson, 2004).

The government responded to and allayed much of the criticism when it published detailed guidance on how the scheme would work in practice, and simultaneously announced both substantial new money for local authorities to pay for the development of services to prevent delays (or to pay acute trusts for the cost of any delays), and a

longer implementation period than initially planned (Henwood, 2004). The new guidance challenged a widespread perception that the scheme was to be used as a ‘stick to beat poor performing social services’ by making clear the responsibilities of both social services and acute trusts; in this respect acute trusts would only be able to charge social services for delays where they had provided a minimum period of notification.

The details of the notification system set out by the Department of Health (DH, 2003) are summarised in Box 1 below.

Whilst social services’ concerns appeared to evaporate as the details emerged, some anxiety about the suitability of the scheme to tackle the problem remained. Two reviews of evidence on the causes of delayed discharges concluded that the new scheme did not offer the local, multi-faceted, ‘whole systems’ approach that was needed (Glasby *et al.*, 2004; Scottish Executive, 2004). Glasby (2004) argued that fundamental change to the structure of health and social care services would be required in order to address delayed discharges.

Box 1 - Interagency notification systems

Initial notification (‘section 2’) of ‘social services’ by hospital staff

- Acute trusts are required to provide notification of ‘social services’ for assessment at least three days prior to discharge, if delays are to be ‘officially reimbursable’.
- Notification of a patient’s potential need for ‘social services’ at discharge should take place either before, or soon after, patient admission.
- Where possible acute trusts should provide an *estimated* date of discharge in the notification.

Second notification (‘section 5’) of ‘social services’ by hospital staff

- A second notification must also be provided by acute trusts of the *confirmed* date of discharge.
- This second notification must be provided to social services at least 24 hours prior to the confirmed date of discharge, and this date should be jointly agreed by the multi-disciplinary team.
- Whilst a second notification may be issued at any time after the initial notification, delays do not become reimbursable until after three full days have passed since initial notification.

The empirical evidence relating to the reimbursement scheme, which was introduced in England in January 2004, is limited. A report of the Commission for Social Care Inspection (CSCI) of progress in seven councils claimed that reimbursement had accelerated the rate of decline in delayed discharges without being divisive of interagency relations. It reported that quality of patient care was variable. In sites where existing joint working was good, and community services well developed, implementing reimbursement had required only minimal readjustment of processes and procedures. However, in other sites where the required range of services was less well developed, it claimed that work to speed up discharge in an inadequate whole health and social care system was potentially "...disempowering individuals and undermining their potential for improvement and rehabilitation" (CSCI, 2004, p.4). CSCI's follow-up investigation in the same sites reported similar findings (CSCI, 2005).

Other research commissioned by the Department of Health on the impact of reimbursement is likely to be published in coming months and will provide new information on staff experiences of using the new system in a range of sites, and systematic examination of the impact of the scheme on patients by comparing experiences in England with those of sites in Scotland where reimbursement was not implemented. In the meantime, this study offers early impressions of the working of the scheme in sites where agencies were already performing well in terms of delayed discharges.

Methods

The study reported here was conducted between June 2004 and March 2005 (a period of consolidation for the reimbursement scheme). It involved 43 qualitative interviews with a stratified sample of health and social care

professionals in six high performing sites across England.

High-performing sites were identified and selected through a multistage process. A statistical model was developed (Fernandez & Forder, 2002) to predict rates of delayed discharge using a variety of funding and services information and to identify sites that outperform the model in terms of their actual rates of delayed discharge. Sites were further short-listed with reference to information about delayed discharge performance over a four-year period, and with reference to joint review reports and star ratings. The authors' final selection of six sites in England ensured that sites represented a mix of geographical locations and local authority types (see Baumann *et al.*, 2007 for full details of the sampling process). The sites selected included:

- four southern sites, including one unitary authority (1), two shire counties (2, 3) and one London borough (6);
- two northern metropolitan boroughs (4, 5).

Interviews were undertaken with a range of health and social care professionals: social services (n=19), acute trusts (n=14), intermediate care staff (n=5) and primary care trusts (n=4). The aim was to interview the key personnel with managerial and operational responsibility for discharge arrangements in each location. Those interviewed in each site included senior strategic staff (e.g. Directors of Nursing and social services Service Managers), operational management/leads (e.g. social services Team Managers and Lead Discharge Co-ordinators in acute trusts) and operational staff (e.g. social services Care Managers and acute trust Discharge Facilitators).

Ward Nurses were not interviewed; it was believed that interviewing Discharge Facilitators, Lead Discharge Co-ordinators

and Directors of Nursing would be adequate to provide a 'health perspective'. However, the omission of nurses is regrettable since it means that the picture provided here of discharge practice is not representative of all the key stakeholders.

The sampling approach was purposive and, notwithstanding the above omission, the intention was to interview the key contacts in each agency at a strategic, team leader and operational level who were involved in the discharge process. The names and contact information for each of the stakeholders interviewed were obtained by way of a snowballing approach. In each site social services team managers were interviewed first, and the range of stakeholders involved in discharge emerged from this and subsequent interviews.

One researcher undertook the fieldwork (MP) and another undertook the analysis (MB). This division of labour was not ideal, since much of the tacit knowledge gained in fieldwork did not contribute directly to the formulation and application of the approach to analysis. However, the second researcher (MB) endeavoured to mitigate the effect of this discontinuity by sharing key interpretations with the rest of the team (including MP).

The interviews did not focus entirely on the topic of reimbursement. As explained earlier, the content of this paper is based on a broader study of good practice in relation to delayed discharge. In addressing these broader aims the interviews covered a range of factors associated with local performance including factors affecting admission rates, systems and processes relating to discharge planning and communication, and, more broadly the organisation and availability of services. In relation to reimbursement, respondents were asked to describe the implementation and impact of reimbursement locally as part of this broader discussion and, due to the timing of the interviews - which was within months of

the commencement of the scheme - discussion of reimbursement formed a substantial part of each interview.

All interviews were tape recorded and fully transcribed. Transcripts were coded (by MB) using a mixture of *a priori* and emergent themes that were agreed with the wider team. Data from each interview, on each theme, were extracted and placed in a thematic matrix, to enable both case wise and cross-case analysis. The findings from this analysis were scrutinised by the interviewer and the wider team (MP). This task was based on an approach to data analysis developed by Ritchie and Spencer (1983) known as the 'Framework Approach'. QSR Nvivo software was used for coding, sorting and retrieving data, and Microsoft Excel was used for data reduction and production of the matrix.

Results

Six main themes emerged from the data regarding the implementation and impact of reimbursement: 1) joint working and prioritisation of delayed discharges at a strategic level; 2) variation in the understanding and implementation of notification systems; 3) reorganisation of social services in some sites; 4) closer monitoring and joint agreement of delays; 5) rates of delays and experiences of cross charging and 6) patient care and outcomes.

Joint working and prioritisation of delayed discharges at a strategic level

Implementation of reimbursement was a key driver of the prioritisation of delayed discharges in all the sites. It required intensive joint work to develop protocols, implement new systems, train staff and commission new services.

In most sites, existing joint working and good relationships at a strategic level provided a positive platform for further work required to implement reimbursement.

In four sites the reimbursement funding had a high profile amongst all agencies. Staff reported positive experiences of working jointly to identify areas where the grant could be spent – such as on the further development of a range of intermediate care, on hospital services designed to prevent admissions and support the discharge process, and on funding care packages. Two of these sites in particular benefited from substantial funding.

Implementation also necessitated the design and interagency agreement of a discharge protocol and notification system that would meet the requirements set out in government guidance. Whilst challenging, in the limited time available for preparation for reimbursement, joint working was, in most sites, positive. Either a joint group oversaw the work or it was undertaken by one agency on behalf of both. In just one site each agency oversaw its own requirements separately, and here agencies had still not agreed the protocol 10 months after implementation of reimbursement.

Variation in the understanding and implementation of protocol and notification systems

Discharge notification systems had been redesigned, based on government guidance, but understanding and implementation varied considerably amongst individual members of staff within and between sites.

This variation in understanding was particularly apparent amongst operational staff. Some ward staff (in sites 1 and 5) provided initial notification (section 2s) of ‘social services’ soon after admission, as detailed in the guidance. Whilst this was largely helpful, social services staff complained that some nurses who sent notifications for assessment at admission did not then communicate with social services until sending final notifications (section 5s) of confirmed date of discharge which could be sent as late as a day before

discharge. As a result social services staff had either to keep chasing ward staff for details of the discharge date in order to avoid any last minute surprises, or they had to be prepared to ‘drop everything they were doing’ at the last minute to finalise the discharge arrangements when they came through:

You get the referral early here, which is great compared to before, but the problem is that nursing staff then think that you are arranging the discharge. But you can't until all the treatment and assessments have been done.

(Care Manager, Social Services, Site 1)

In other sites (2, 3, 4 and 6) initial and follow up notification timescales varied. Some nurses were sending initial notifications well in advance but, according to social services staff, many nurses still provided initial notification as late as three days before discharge. Social services staff in site 4, who commonly received initial and follow up discharge notifications within a day of each other, were not involved in setting discharge dates and staff here were regularly trying to make arrangements within 24 hours of notification from nurses of an intention to discharge:

the pressure we're under is not sustainable, we're going to have to go back to the Trust and get them to work under reimbursement criteria. ... We can't be getting people discharged the same day...

(Team Manager, Social Services, Site 4)

Social services respondents in site 3 reported that late arrival of initial notification was not a problem for them as staff were always involved in setting actual discharge dates with trust staff.

The use of ‘estimated date of discharge’ was new to most sites, and its inclusion in initial notifications (section 2s) was inconsistent. Where it did happen, the reported benefits

were that both health and social care staff who were notified of the date could plan their assessments and services accordingly, and discharge teams could more easily monitor progress. Health and social care staff in all but one site (site 3) reported that ward staff had only a limited understanding of what was required of them under the new notification system, despite support from discharge teams and local training opportunities:

I mean we're still struggling out on the wards 'cause you'll go up on the wards now even 18 months down the line and you'll ask "have you completed your section 5?" and they'll say "what's a section 5?" despite huge amounts of training". (Discharge Process Manager, Acute Trust, Site 6)

It may be that, whilst arranging discharge is the key role of many of the staff we spoke to, it is just one part of the work of a nurse and, with such large numbers of nurses, compared to care managers or discharge facilitators, it is perhaps unsurprising that the arrangements were taking a longer time to become embedded in nursing practice.

Reorganisation of social services in some sites

In sites 2, 3 and 4 social services teams based in the hospitals were responsible for arranging post-discharge care for all clients (both new and existing) who were referred by ward staff. In these sites proximity and familiarity with the pace of hospital working and with the staff involved meant that a relatively rapid social services response could be provided to any notification for assessment from ward staff.

Prior to reimbursement, in sites 1, 5 and 6, hospital teams were only responsible for arranging discharge of clients who were new to social services. Where a client was already known to social services, hospital teams had to pass on the notification to

community teams who would then come to the hospital to assess the patient and arrange discharge. Community teams were reportedly unable to respond as quickly as hospital staff but it was believed that they provided continuity of care which was valued by patients. Following reimbursement's implementation, these arrangements were reviewed. In sites 5 and 6, due to the need to speed up the pace of work to avoid having to make payments, hospital social services teams now took on all referrals from the wards and community teams were no longer involved until the discharge had been arranged. Furthermore, care managers in these sites had been assigned to specific wards with the aim of providing improved team working. In site 1 restructuring along these lines was being considered.

Staff from both health and social services reported improved relations between ward staff and care managers as a result of these changes and, in site 5, multi-disciplinary team (MDT) meetings were now frequently occurring, where previously they had not:

The ward staff like it a lot better ... they used to complain that they might have six or seven social workers coming on the ward every day, they didn't know who was who ... So now there are dedicated workers the ward know exactly who the workers are. And a lot of wards are now having weekly multi-disciplinary team meetings to consider complex cases.

(Team Manager, Social Services, Site 5)

Closer monitoring and joint agreement of delays

The need for close monitoring and joint agreement of delays is a key requirement of the reimbursement scheme. Social services and hospitals reported that since reimbursement they had started monitoring patient discharge progress on a daily basis. In addition, in almost all sites weekly meetings (at team leader level) were held to

agree formally the numbers of delays and the agency responsible. In sites 1 and 6, staff also commented that these meetings provided a positive basis for identifying and preventing risk of delays.

Staff reported that agreeing responsibility for delays was generally straightforward; both the notification protocols that had been developed and the Department of Health guidance around reporting weekly delays provided a firm basis for deciding which agency was responsible. For example:

if there's a debate or dispute [the Deputy Director] will get involved and she will involve her counterpart in Social Services and they'll decide, but even that would rarely be the case. ... There's an understanding of what the rules are. (Director of Nursing, Acute Trust, Site 3)

Rates of delays and cross charging

Staff in four sites (2, 3, 5 and 6) believed that there had been a fall in numbers of social services delays since implementation of the reimbursement scheme but it was often mentioned that rates of delays were already low (or falling).

The responsibility for low/falling delays was commonly attributed to existing good communication and working relationships and well developed health and social care infrastructure but there was a perception that the risk of charges (sites 2 and 5) and the extra resources provided by reimbursement grant (especially sites 2 and 3) had also made a contribution.

Social services and health staff in a number of sites reported that, as a result of the notification protocols and reimbursement money, the only delays remaining were those that were the responsibility of the acute trust:

Well I think we're finding very little now ... it's changed a lot. Now the

reimbursement money has been put in, there's very little reimbursable delay. In other words, most of it is health delay but, yes, there's not much delay full stop. (Senior Management, Acute Trust, Site 3)

Patient care and outcomes

There was some discussion in staff interviews of patient care and outcomes. In three sites (2, 3 and 6) reimbursement was praised for providing additional funds for service development. Some staff commented that newly developed intermediate care services meant patients now had a greater chance of returning home than previously.

In most sites people with mental health problems were, according to staff, most likely to experience long delays due to the limited number of psychiatric staff available to make assessments, and the limited availability of post-acute health and social care for this group. In Site 3, however, a substantial (£1m) reimbursement grant had been used specifically to develop a range of community-based services for older people with mental health problems, enabling significant progress to be made with backlogs of delays for this group.

Some social services staff in three of the sites stressed that the reimbursement scheme had increased the pressure on care management staff to work more quickly with patients on arranging discharge. Some social services staff felt that this pressure did not allow them to support patients adequately in regard to key decisions about their future living arrangements and care needs:

but it's this very quick turnover that I can't get to grips with, especially for placements, because ... you've got to work with families; to come to terms with that ... it just doesn't seem to be good practice. We're rushing people into

making decisions. (Operational Staff, Social Services, Site 2)

In two sites, there were some fears amongst social services staff that some patients had been discharged too early, although these respondents were not sure if this was a systematic trend.

Discussion

Like the CSCI studies (CSCI, 2004; CSCI, 2005) we found that reimbursement had not undermined relationships in our study sites. At a strategic level the introduction of reimbursement has provided new opportunities to work together in commissioning new services and in designing the new notification systems. At an operational level the notification system is largely perceived to be a step in the right direction towards further clarifying responsibilities and enabling staff to communicate effectively and in a timely manner regarding discharge. However, greater exposure and engagement with the guidance on discharge could be helpful for nurses whose interpretation and understanding of the guidance is reportedly inconsistent.

The payments system has prompted closer monitoring of delays and joint working amongst health and social care staff at team manager level to avoid delays. The notification system has been helpful to the process of agreeing the attribution of responsibility for delays between hospitals and social services and, in these sites, has largely been accompanied by a growing recognition amongst health staff that most delays are 'health delays' rather than a result of delay by social services. Glasby (2004) has also highlighted the growing evidence that a substantial proportion of delays are the result of 'internal hospital inefficiencies' in his review of the hospital discharge literature. In this respect, the reimbursement scheme appears to have

provided a long overdue system of arbitration.

In some sites reimbursement has precipitated a change to the balance of work undertaken by care managers in hospital and community teams. Due to reimbursement, social services teams based in hospitals now tend to arrange all discharges (both new and existing clients), transferring responsibility to community teams only for follow up and ongoing care management. This represents a more efficient way of dealing with discharge arrangements and appears to have positively affected interagency relationships (through supporting closer interagency working), but there were concerns amongst social services staff that this efficient discharge had been achieved with a cost to continuity of care management. The value attributed by patients to continuity of care is highlighted by the CSCI report which found that "... older people really appreciated having a single named person to oversee, monitor and adjust care services in response to their changing needs" (CSCI, 2005, p.5). That reimbursement may be undermining this is of concern.

Whilst there was comment from some social services staff about an increased likelihood for 'hurried' discharge this was not something that hospital staff spoke about. Glasby (2004, p.597) has argued that health and social care agencies "operate according to competing notions of good practice" in which hospitals prioritise efficient throughput and social care practitioners emphasise the importance of adequately supporting patients to make difficult decisions about their future care. The difference of opinion found in this study regarding whether discharge is 'timely' or 'hurried' is surely a reflection of the different mindsets underpinning good practice in health and social care.

Social care and health staff however expressed concerns about the lack of impact the scheme would have on speeding up

discharge of those patients excluded from it such as patients with mental health problems who often stay in hospital for prolonged periods while they wait for assessment or available community-based services. Whilst this outcome was foreseen by commentators (Moss, 2004), the exclusion of these patients was perhaps a recognition on the part of the government that addressing the shortages of psychiatric staff and developing good quality community-based services across the country would take time and substantial funding. And, in this respect, it was perhaps an acknowledgement of the limitations of the reimbursement scheme.

There are limitations to this study as noted earlier and it is helpful to recapitulate some of these before moving on to draw conclusions. Firstly, the results are taken from a much broader review of the factors supportive of timely discharge in high performing sites. It is not a representative study of the implementation of reimbursement in a broad range of sites. As we have already noted, this limits the conclusions we can draw on the implementation of reimbursement. A second issue, linked to this, is that the interviews did not focus entirely on the topic of reimbursement – our findings relating to reimbursement are based on what respondents chose to talk about. Had the interviews systematically covered the full range of issues relating to staff perceptions of the implementation of reimbursement, the study findings would be based on a more comprehensive analysis. Since this was not the case it was not always possible to find information on all the main themes from the interview data. A third issue is the omission of interviews with nurses. Although interviews with a range of health staff were undertaken, it would have been valuable to examine nurses' perspectives on factors affecting their discharge planning especially given the research evidence in the literature (Payne *et al.*, 2002) and from the present study, which suggests that nurses' limited

understanding of discharge issues is sometimes a key factor hampering efficient discharge communication.

Conclusion

Staff views from these high performing sites may reflect some of the experiences of staff in other sites in England but, since these sites are anomalies by virtue of their pre-existing success in tackling delayed discharges, care should be taken in making inferences from this small study. Indeed, because existing relationships were, by and large, good in these sites, it may be that reimbursement has been easier to implement than in sites where relationships are less well established.

The implementation of reimbursement in these sites has provided a sound basis for continued positive joint working at both strategic and operational levels. There was very little evidence to suggest that its implementation has had a negative effect on interagency relationships. The clarity brought by new protocols, regarding the balance of responsibilities between agencies, and the extra resources provided to sites for implementation of the scheme, may have been fundamental in supporting joint working. Operational efficiency appears to have made some gains, but further work is needed to ensure that nurses, who are key drivers of discharge, fully understand the system.

Whilst, in general, it appears that patients are more likely to receive timely discharge from hospital as a result of the new scheme and that monies provided through reimbursement had in a number of sites been used to develop new services, there is also some evidence that suggests that reimbursement may have had some negative impacts on some patients, by reducing the time available to them to consider their options and by affecting the continuity of their care. The ongoing issue of delayed discharge for people with mental health

problems has largely been unaffected by reimbursement due to their exclusion from its provisions.

Further research (described earlier) has been commissioned by the Department of Health specifically to explore the impact of reimbursement and we expect that this research will shortly provide a full account of its implementation, including its impact on patient care and outcomes.

References

- Andersson, G., & Karlberg, I. (2000) 'Integrated care for the elderly: the background and effects of the reform of the Swedish care of the Elderly', *International Journal of Integrated Care*, **1**(October-December 2000), pp.1-10.
- Baumann, M., Evans, S., Perkins, M., Curtis, L., Netten, A., Fernandez, J., & Huxley, P. (2007) 'Organisation and features of hospital, intermediate care and social services in English sites with low rates of delayed discharge', *Health and Social Care in the Community*, **15**(4), pp.295-305.
- Commission for Social Care Inspection (2004) *Leaving Hospital – The Price of Delays*, London: CSCI.
- Commission for Social Care Inspection (2005) *Leaving Hospital Revisited*, London: CSCI.
- Department of Health (2002) *Delivering the NHS Plan: Next Steps on Investment, Next Steps on Reform*, London: Department of Health.
- Department of Health (2003) *The Community Care (Delayed Discharges etc.) Act 2003: Guidance for Implementation*, London: Department of Health.
- Fernandez, J. & Forder, J. (2002) *The Importance of Social Care in Achieving an Efficient Health Care System: The Case for Reducing Hospital Delay Discharge Rates*, LSE Health and Social Care Discussion Paper 07, London School of Economics.
- Glasby, J. (2003) 'Delayed reaction' *Community Care*, July 10, pp.38-9.
- Glasby, J. (2004) 'Discharging responsibilities? Delayed hospital discharges and the health and social care divide', *Journal of Social Policy*, **33**(4), pp.593-604.
- Glasby, J. & Littlechild, R. (2004) *The Health and Social Care Divide*, Bristol: Policy Press.
- Glasby, J., Littlechild, R. & Pryce, K. (2004) *Show Me the Way to go Home: Delayed Hospital Discharges and Older People*, Report to the Department of Health, University of Birmingham.
- Henwood, M. (2004) *Reimbursement and Delayed Discharges*, Discussion paper for the Integrated Care Network, Leeds, Integrated Care Network.
- House of Commons Select Committee on Health (2002) *Delayed Discharges, 3rd Report 2001-2*, London: HMSO.
- Moss, G. (2004) 'Community Care (Delayed Discharges) Act – psychiatric patients specifically excluded', *British Medical Journal*, web document: <http://www.bmj.com/cgi/eletters/328/7430/4#45957>.
- National Audit Office (2003) *Ensuring Effective Discharge of Older Patients from NHS Acute Hospitals*, London: The Stationery Office.
- Payne, S., Kerr, C., Hawker, S., Hardney, M. & Powell, J. (2002) 'The communication of information about older people between health and social care practitioners', *Age and Ageing*, **31**(2), pp.107-17.

Ritchie, J. & Spencer, L. (1993) 'Qualitative Data Analysis for Applied Policy Research', in Bryman, A. & Burgess, R. (eds.), *Analyzing Qualitative Data*, London: Routledge, pp.173-94.

Rowland, D. & Pollock, A. (2004) 'Choice and responsiveness for older people in the "patient centred" NHS', *British Medical Journal*, **328**(7430), pp.4-5.

Schimmel, E.M. (1964) 'The hazards of hospitalization', *Annals of Internal Medicine*, **60**, pp.100-10.

Scottish Executive (2004) *A Research Review on Tackling Delayed Discharge*, Edinburgh: Scottish Executive.

Taraborelli, P. (1998) *Hospital Discharge for Frail Older People: A Literature Review*, London: The Stationery Office.

Victor, C.R., Healy, J., Thomas, A. & Seargeant, J. (2000) 'Older patients and delayed discharge from hospital', *Health and Social Care in the Community*, **8**(6), pp.443-52.

Wilkinson, D.G. (2004) 'Choice is even more restricted for elderly mentally ill', at <http://www.bmj.com/cgi/eletters/328/7430/4#45202>

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Involving older service consumers in health research: action research as a strategy for promoting involvement

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Abstract

This paper considers the extent of older service consumer involvement in health-related research and, through a critical consideration of the literature, explores the levels and ways in which older service consumers are involved. Having considered the context of consumer involvement in health research we differentiate that involvement in previous studies along a continuum from passive participation to active, independent participation, and consider the strategies that support the differing levels of involvement. The experiences of research involvement from the perspectives of both older service consumers and professional researchers are explored, and the benefits of, and difficulties facing, such partnerships are considered. The importance of education and training for both older service consumers and professional researchers for such partnership working is highlighted, and strategies for enhancing effective involvement in planning, designing and managing research are suggested. The benefits of utilising an action research approach to promote and support consumer involvement are considered and the processes for developing this approach as a key strategy for promoting older service consumer involvement explored.

Keywords: Older people, research involvement, action research

Introduction

The move away from a paternalistic model of health care provision towards one where decision-making is shared between service consumer and service provider has taken place across different healthcare settings. This includes the care of the older person where maximising the participation of older people in active decision-making concerning their treatment continues to be an important policy driver (Department of Health, 2006). Alongside the increased involvement of service consumers in determining the care they receive is a parallel move towards their increased participation and partnership in research designed to develop the services they use. In this model of research, service consumers are no longer consigned to the passive role of subject where research is conducted upon them. Rather, they are able to participate in

a more active way, as part of the research team.

Reed *et al.* (2004) note that there are a number of degrees or levels of involvement ranging from service consumers as data sources, through service consumers as partners in research, to service consumers as independent researchers. The latter two levels of participation may involve service consumers developing research guidelines, developing methodology and research tools, collecting and analysing data, interpreting findings and writing up.

This paper examines the extent to which older service consumers are included in healthcare research as active participants and considers how an action research approach can be utilised as a strategy to promote involvement of older service consumers in health research. The term 'consumer' rather than 'user' has been

chosen as the preferred terminology as it encompasses a broader concept of both current and potential 'user' (Ross *et al.*, 2005). The term 'professional researcher' is used to identify those employed as researchers and distinguish them from consumers who are undertaking research.

Involvement of older people in health research: the background

The Involve library and the National Institute of Health library were searched for relevant published and unpublished literature. In addition, the following electronic databases were searched: CINAHL (1982 to June week 1 2007), AMED (1985 to June 2007), British Nursing Index and Archive (1985 to May 2007), OVID MEDLINE (R) (1950 to May week 5 2007), PsycINFO (1985 to June week 1 2007). The search terms used were: older person; elderly; geriatric and consumer involvement; consumer participation; patient involvement; patient participation; action research; research methods; research methodology.

A number of authors have considered the impact of older consumer involvement in health research, and, whilst such involvement has been identified as beneficial (Davies & Nolan, 2003; Tetley *et al.*, 2003; Barnard *et al.*, 2005; Dewar, 2005; Paterson *et al.*, 2005; Ross *et al.*, 2005), a number of important issues that need to be addressed have been identified. These include challenges to notions of power, status and accountability (Ross *et al.*, 2005), the need to clarify the role of the consumer (Barnard *et al.*, 2005; Dewar, 2005), and the need to acknowledge negative experiences of involved consumers. Studies involving older service consumers in health research have been carried out in England (Reed *et al.*, 2002; Tetley *et al.*, 2003; Greenhalgh *et al.*, 2005; Ross *et al.*, 2005), Scotland (Tolson *et al.*, 2006), Canada (Gallagher & Scott, 1997; Moyer *et al.*, 1999), and Australia

(Chenoweth & Kilstoff, 1998; Ritchie *et al.*, 2003; Richardson & Reid, 2006). Clinical settings included diabetic care (Greenhalgh *et al.*, 2005), dementia day care (Chenoweth & Kilstoff, 1998), primary care (Moyer *et al.*, 1999; Ross *et al.*, 2005) psychology (Richardson & Reid, 2006), and in-patient hospital care (Reed *et al.*, 2002). Other studies focused on general care provision and nursing care (Ritchie *et al.*, 2003; Tetley *et al.*, 2003; Tolson *et al.*, 2006).

In addition to involving older people in the research process, other stakeholders were involved by researchers. These included nurses (Moyer *et al.*, 1999; Tolson *et al.*, 2006), healthcare practitioners (Gallagher & Scott, 1997; Chenoweth & Kilstoff, 1998), 'local experts' (Richardson & Reid, 2006), bilingual health advocates and their managers (Greenhalgh *et al.*, 2005), people with disabilities (Gallagher & Scott, 1997), health and social care practitioners (Ross *et al.*, 2005) and family carers (Chenoweth & Kilstoff, 1998). The degrees to which these older people participated, echo those discussed by Reed *et al.* (2004), ranging from a relatively passive role to an active role as a fully independent researcher. These studies can be differentiated along a continuum from passive participation to active, independent participation, and the strategies that supported the differing levels of involvement identified.

Older people have participated in research in a more passive way in the studies by Moyer *et al.* (1999), Richardson and Reid (2006) and Greenhalgh *et al.* (2005). Moyer *et al.* (1999) report on a study that was undertaken with the aim of developing approaches to gain access to older adults at risk of losing their independence. The approach taken was to make contact through community networks in order to develop an understanding of their situation. The authors describe a cyclical approach to defining the problem, initiating action and evaluating change, although the level of involvement of the older people at risk did

not appear to move beyond the research participant level. Richardson and Reid (2006) describe an action research project to develop and evaluate a group cognitive-behavioural therapy (CBT) programme for older adults experiencing depression. They describe the participants in the action research process as “service consumers and service providers” (p.62). However, service consumers only participated by completing the pilot CBT programme and providing data concerning its effectiveness through completing quantitative and qualitative assessment tools. Greenhalgh *et al.* (2005) report on an action research project to develop group education and support for bilingual health advocates and elderly South Asian patients with diabetes. The authors worked with local health care staff and service consumers to assess need, train staff, set up and evaluate the education and support groups. Service consumers were involved to a lesser extent than staff and appear to have contributed to the research at the evaluation stage only by participating in focus groups and being observed by the researchers. Whilst the authors of these two papers describe this involvement as action research, arguably it does not differ from a traditional model of research in which patients and service consumers act as subjects.

Older people took more active roles in the projects described by Tolson *et al.* (2006), Chenoweth and Kilstoff (1998), Gallagher and Scott (1997), Ross *et al.* (2005) and Ritchie *et al.* (2003). Tolson *et al.* (2006) report on the first five years of a participatory research project to develop approaches to promote the attainment of evidence-based nursing care for older people in Scotland. The authors adopted an action research methodology that included older service consumers, although neither the number of older people nor the exact nature of their involvement throughout the project were clearly stated. Areas of the research where older people were involved include testing the feasibility of creating an

online community of older people and carers to collaborate on the development of resources for older people. In this phase of the project, older people were actively involved in developing resources designed to be used by older people and their carers to make their expectations and aspirations known when care is required.

Chenoweth and Kilstoff (1998) report on a participatory action research project undertaken in Australia to design, implement and evaluate a new therapy programme in a multicultural day-care centre for people with dementia. The research participants included the researchers, who acted as facilitators for the study participants, the day-care staff, family carers and day-care clients. Although the day-care clients were involved in the research to a lesser extent than were day-care staff and family carers (for example, staff and carers participated in focus groups and in-depth interviews whilst day-care clients did not), day-care clients did contribute to the research process by helping to develop an outcome measurement tool. Given the difficulties the authors experienced working with day-care clients suffering from dementia - many of whom did not speak English as their first language - these efforts to include service consumers are to be applauded.

Gallagher and Scott (1997) report on an action research project, undertaken in Canada, to identify and rectify factors contributing to slips, trips and falls in public places by older people and by people with disabilities. Research partners in the project included older people, people with disabilities, health practitioners and professional researchers. These stakeholders were consulted in order to establish project goals, develop methods and prepare for the dissemination of findings. However, the authors do not describe the exact tasks that research partners undertook nor whether different stakeholder groups participated in the research in different ways. Older people

were also involved in data collection, being both the study participants from whom data were collected, via a telephone-administered questionnaire, and data collectors who administered the questionnaire.

Ross *et al.* (2005) report on their experiences of older consumer involvement within a project carried out in a primary care setting that aimed to explore older people's expectations, priorities and need for information in relation to the risk of falls. Older service consumers were involved on a number of levels, including project design and management, analysis and dissemination of findings. A key component of the project was the establishment of a consumer panel that worked in partnership with the research team. The need for carefully constructed, regular and individualised communication was highlighted, as was the level of commitment required from the research team. Whilst both service consumers and the involved consumers generated a number of 'top tips' for improving the experience of involvement, the strategies for implementing these were not explored in depth.

Ritchie *et al.* (2003) report on an Australian pilot study to explore whether retirement village residents could be empowered to address issues of concern regarding their health and well-being. Participatory action research methods were used and the residents of three urban retirement villages were invited to be co-researchers. Residents were aged between 65 and 91 years and were living in self-care accommodation. The authors report that residents became actively involved in identifying major concerns and went on to participate in groups that addressed the issues identified, although they do not state how many residents became involved. The activities these groups undertook included negotiating with the local council, setting up a newsletter and liaising with village managers. In some cases, residents

undertook these activities alone, in others they were assisted by a professional member of the research team.

Older people adopt a very active role in some research projects (Reed *et al.*, 2002; Tetley *et al.*, 2003; Reed *et al.*, 2004; Ross *et al.*, 2005). Reed *et al.* (2004) discuss two studies where older people were greatly involved in the research process. The first investigated recent developments in discharge planning in Newcastle Health Authority (Reed *et al.*, 2002). In this study, older people were involved in a range of roles as interviewers, data analysers, report writers, editors and as co-author of a journal article. The second study (as yet unpublished) examined the issues that older people felt most affected their quality of life after retirement. In this study, the older person acted as an independent researcher, initiating the study and obtaining the training and resources needed to undertake the research.

Tetley *et al.* (2003) describe the experience of establishing and working in a research partnership exploring people's involvement in decision-making processes when using care services in later life. The authors, who include some of the older people from the partnership, describe the circumstances leading up to the establishment of the research partnership when the lead author initiated a research project to explore older people's involvement in decision-making processes when using care services. A total of seven older people became involved in the research and undertook tasks including advising and supporting the lead author on the project, attending and participating in meetings held by the regional National Health Service Executive and presenting at regional conferences. Specifically, the older people advised the lead author about the participant consent forms and participant information sheet, liaised with potential participants and assisted in obtaining consent.

In Chenoweth and Kilstoff's (1998) study, the benefits of participation that day-care clients reported included being empowered to make changes and providing companionship. These findings are echoed by Ritchie *et al.* (2003) and Tetley *et al.* (2003). Ritchie *et al.* (2003) report that residents valued the opportunity to clarify mutual concerns and to make collective decisions on changes that could enhance their own health and well-being. Tetley *et al.* (2003) report that the research resulted in personal gains for the older people who participated, including companionship and support. The study reported by Ross *et al.* (2005) highlighted the very positive way in which service consumers reported on their involvement, in terms of both the personal benefit they received (e.g. gaining an opportunity to learn about falls) and the input they gave to the study. The members of the consumer panel were subsequently able to realise their aspirations to make a contribution to on-going, local policy development, through engagement in key decision-making groups within the PCT. The degree to which the consumers' experience of involvement in research is addressed in the research reports is somewhat limited. There appears to be a tendency to focus on how the professional researchers experienced this involvement, both positive and negative. Where the consumers' experience is reported, this is, in the main, reported positively but whether this signifies that such involvement is always positive or whether negative experiences are under-reported is unclear.

Action research: an approach to maximising participation

There appears to be a stronger body of evidence for involving older users in studies that have used an action research approach (Gallagher & Scott, 1997; Chenoweth & Kilstoff, 1998; Ritchie *et al.*, 2003; Greenhalgh *et al.*, 2005; Richardson & Reid, 2006; Tolson *et al.*, 2006) than for any other research approach. Although, as

discussed above, the claims of some studies to have used an action research approach are not always fully substantiated, there have been significant developments in terms of the models of participatory research that promote older service consumer involvement (Hanson *et al.*, 2006). Action research is a method arising out of critical social theory, the aims of which are for group members to gain authentic insight into their problems and to make decisions about future goals that are both useful and empowering. In truth, action research refers less to a specific research technique and more to a set of principles underlying the conduct of an inquiry (Reason, 1988). The principles intrinsic to this approach are participation and collaboration in creating knowledge from experience, application of this knowledge as action for change and collective reflection towards ownership of what has been learned. Hence, participation by all group members is written into action research and present at all stages. Indeed, recent developments have emphasized the participatory nature of action research and its potential for democratising knowledge. Thus, Gergen (2003) discusses the relationship between action research and 'orders of democracy' noting that action research can contribute to a 'first-order democracy', by bringing people together in action and discussion, and to a 'second-order democracy', by providing a process of action, analysis and reflection through which conflict can be resolved.

King (1995) discusses four areas of benefit stemming from the participatory nature of action research that provide support for the method:

1. Benefits to the individuals who participate in the process, including trained researchers who will be challenged to justify their actions and interpretations;
2. Improved practice: those who work to create change will be more committed to bringing these changes to fruition;

3. Improved theory: a theory that incorporates the knowledge of, and is constructed by, those to whom it will apply will be of greater practical relevance;
4. Improved opportunities for meaningful social change.

Action research operates within a different paradigm to more traditional forms and King (1995) argues that new concepts of validity and reliability are required. Waterman (1998) concurs, arguing that the validity of action research does not rest on the generation of generalisable knowledge. The author suggests three forms of validity appropriate to action research relating to the principles of participation, contextual relevance and the aim of democratising knowledge. It is suggested that it is on the basis of the following that the validity of an action research study should be judged:

1. Dialectical validity: relates to the way in which an action research study engages with debates about problems and solutions with a range of participants in an attempt to improve a situation;
2. Reflexive validity: relates to the extent to which the project has considered the limitations of the study and the strengths of what has been achieved;
3. Critical validity: relates to the moral responsibilities to promote inclusivity and emancipation.

Whilst the action research model would seem to encourage the involvement of service consumers, as well as healthcare providers and trained researchers, Dewar (2005) notes that, when it comes to older service consumers, a number of assumptions work against their full participation. For example, assumptions are often made that growing old inevitably results in reduced capacity for involvement in decision-making, that older people are not sufficiently prepared to be able to articulate their opinions, and that they lack the

confidence to express themselves. Dewar argues that these ageist attitudes mean that older people are often excluded from participation in research. Reed (2005) highlights that communication and ownership of research at the practice level can sometimes come into conflict with funding and project management processes and procedures.

Using an action research approach to promote older service consumer involvement

Both theory and research strongly suggest that the involvement of older service consumers in research is beneficial, offering pragmatic and ethical benefits to both the process and the outcome of a research project. However, the extent to which older service consumers have been involved can be seen to be variable and, in relation to the more passive level of involvement (for example, Richardson & Reid, 2006), it is not easy to distinguish clearly how this differs significantly from the more traditional role played by service consumers as the 'subjects' of research.

When individuals from different backgrounds, with different experiences, skills and different access to resources come to work together, there is a risk that such differences will translate into an unequal distribution of power. Reed *et al.* (2004) stress that professional researchers need to question both their motivations for, and the likely outcomes of, involving older people in research, to examine whether involvement will be empowering or exploitative. Will their involvement see a true partnership where lay people participate fully and equally, or will an inequitable distribution of power frustrate this aim? Evidence from research reflects this concern, suggesting that this method of working presents challenges that need to be overcome if older people are to participate effectively and make a real contribution to research.

Firstly, prejudice on the part of professional researchers needs to be overcome. Whilst this may echo the ageist attitudes present in wider society (Dewar, 2005), Reed *et al.* (2004) note that such prejudice may feature in all attempts to involve service consumers in research, particularly if researchers seek to apply traditional scientific notions of objectivity and rigor. Hence, efforts to provide education to professional researchers to encourage them to re-think their conceptions of older people should be accompanied by education concerning the value and possibilities offered by other research paradigms, in particular the benefits offered through a more participatory action research approach. Hubbard (2004) identifies how a number of user-led organisations have been taking a lead in developing capacity in participatory and emancipatory research. Encouraging professional researchers to engage in a more thoughtful consideration of what methods might be appropriate to the types of research question being addressed in areas that are significant to older people could generate work in which older people are centralised as initiators and managers of research, rather than being somewhat marginalised in the more passive role as research subjects. Such education should provide concrete examples of successful projects and the benefits that are associated with a different way of working, in order to enable professional researchers to appreciate fully the important role that older service consumers can play in strengthening the validity and credibility of research.

Secondly, there are resource issues involved in the inclusion of older people as partners in research. The successful engagement of older people entails both time and material resources, including the training of both the involved service consumer and the professional researchers. Whilst, with the increasing awareness of the importance of involving service consumers in research, such training could be argued to be core to the basic training of all researchers, the

training required by service consumers – both as individuals and groups – will inevitably require costing as part of the core research project budget (Ross *et al.*, 2005) and the time required for such activity may not always be easy to estimate. In addition, service consumers should be paid and have all their expenses met, in accordance with the principles of good practice outlined in the guidance from INVOLVE (2006).

Thirdly, the specific skills that older people need to participate fully in the research process have to be clearly identified. Dewar (2005) describes developments at the Royal Bank of Scotland Centre for the Older Person's Agenda, initiated to support the involvement of older people in research. The core of the Centre's programme has been the development, implementation and evaluation of education that enables older people to participate in partnership working with a greater degree of confidence. The content of this education has included learning specific skills related to the research and policy process, as well as learning that relates to building confidence and working in partnership. Evaluation of the course revealed that participants felt they had achieved several things. These included developing a more critical approach, increased confidence, increased awareness of social and political issues, increased ability to confront situations and enhanced communication skills. 'Graduates' of the programme have gone on to participate in a variety of projects, including research and writing for publication. Although the benefits resulting from this programme are evident, it should be noted that the minimum age for participation is 50 years and while it can be argued that those aged 50 years and above are, indeed, 'older', individuals in their 50s are not 'older service consumers' in the sense understood in the literature relating to the care of the older person. Although the authors do not provide any information concerning the ages of those who have, to date, participated in the programme, they

note that recruiting participants to the programme from 'hard to reach' groups, including older people in care homes, frail older people, and people from ethnic minorities remains a challenge. However, the provision of any such education to older service consumers may undermine the aim of democratising knowledge by reinforcing the belief that only those who have received the requisite training can participate in research.

Conclusion

In this article, we have considered a range of models and strategies used to engage older service consumers in research, across a range of health care settings. However, it can be seen that there are some core structures and processes that could be usefully adopted by research teams and their service consumer partners:

Project planning

In order to present to commissioners of research a comprehensive proposal, research teams need to work in partnership with service consumers from the earliest stages of planning. This will enable strategies for developing and sustaining the required level and cost of involvement throughout the life of the project to be clearly identified. This planning stage must consider fully not only the methodology and methods of the project but also the project management strategy. A key component at this stage is to identify who will be involved, how they will be involved and what training they need in order to be effectively involved. Such training will need to be funded and it is possible that this could limit funding opportunities - in that applications would only be made to those commissioners willing to consider proposals that included training costs. However, even when such costs are fully met, what is not built into funding bids is the development of the funding bid itself and, if service consumers are to partner professional researchers in this development, it needs to be recognised

that funding such involvement is part of the core cost for organisations which undertake research. This is an obvious limitation to the inclusion of service consumers in developing funding bids, as only those organisations with existing resources are able to budget for such involvement.

Project design

The process of developing the methodology and methods of the study can be an area where tensions arise between the 'expertise' of the professional researchers and the experience of the consumer. Participatory working arrangements that build the confidence of the consumer, whilst demonstrating the value of the consumer perspective, are an important strategy to address this potential tension. Creative ways of developing consumer involvement need to be sought and this, in itself, may be an important factor in project design, perhaps requiring an eclectic rather than purist approach to the selection of methods to be employed in the collection and analysis of data. Where necessary, training for both the professional researchers and consumer researchers that enhances their skills in new ways of working should be beneficial.

Project management

There is a risk that the perceived 'expertise' of the professional researchers and the stringent requirements of research governance structures and processes will diminish the potential for effective consumer involvement in the management of the project. The skills that older consumers bring with them to the project need to be identified and utilised. Similarly, the skills developed in the course of the project should be recognised and built on. Project management structures that are non-hierarchical, yet with clear lines of communication, responsibility and accountability may well offer the best option for enhancing consumer involvement in the management of research projects.

References

- Barnard, M., Britten, N., Purtall, R., Wyatt, K. & Ellis, A. (2005) *The PC11 Report: An Evaluation of Consumer Involvement in the London Primary Care Studies Programme*, Exeter: Peninsula Medical School.
- Chenoweth, L. & Kilstoff, K. (1998) 'Facilitating positive changes in community dementia management through participatory action research', *International Journal of Nursing Practice*, **4**(3), pp.175-88.
- Davies, S. & Nolan, M. (2003) 'Nurturing research partnerships with older people and their carers: learning from experience', *Quality in Ageing – Policy, Practice and Research*, **4**(4), pp.2-5.
- Department of Health (2006) *Partnerships for Older People Projects: Making the Shift to Prevention*, London: Department of Health.
- Dewar, B.J. (2005) 'Beyond tokenistic involvement of older people in research – a framework for future development and understanding', *International Journal of Older People Nursing*, **14**(3a), pp.48-53.
- Gallagher, E.M. & Scott, V.J. (1997) 'The STEPS project: participatory action research to reduce falls in public places among seniors and persons with disabilities', *Canadian Journal of Public Health*, **88**(2), pp.129-33.
- Gergen, K. (2003) 'Action research and orders of democracy', *Action Research*, **1**(1), pp. 39-56.
- Greenhalgh, T., Collard, A. & Begum, N. (2005) 'Narrative based medicine: an action research project to develop group education and support for bilingual health advocates and elderly South Asian patients with diabetes', *Practical Diabetes International*, **22**(4), pp.125-9.
- Hanson, E., Magnusson, L. & Nolan, J. (2006) 'Developing a model of participatory research involving researchers, practitioners, older people and their family carers: an international collaboration', *Journal of Research in Nursing*, **11**(4), pp.325-44.
- Hubbard, G. (2004) 'Users or losers: does the rhetoric of user involvement deliver?', *Research Policy and Planning*, **22**(1), pp.53-6.
- INVOLVE (2006) *Guide to reimbursing and paying members of the public actively involved in research: for researchers and research commissioners (who may also be service consumers)*, accessed 20/09/07 at http://www.invo.org.uk/pdfs/Payment_Guidefinal240806.pdf.
- King, J.A. (1995) 'Bringing research to life through action research methods', *Canadian Journal on Aging*, **14**(suppl. 1), pp.165-76.
- Moyer, A., Coristine, M., Jamault, M., Roberge, G. & O'Hagan, M. (1999) 'Identifying older people in need using action research', *Journal of Clinical Nursing*, **8**(1), pp.103-11.
- Paterson, C., Allen, J., Browning, M., Barlow, G. & Ewings, P. (2005) 'A pilot study of therapeutic massage for people with Parkinson's disease: the added value of user involvement', *Complementary Therapies in Clinical Practice*, **1**(3), pp.161-71.
- Reason, P. (1988) *Human Inquiry in Action: Developments in New Paradigm Research*, Newbury Park: Sage.
- Reed, J. (2005) 'Using action research in nursing practice with older people: democratizing knowledge', *Journal of Clinical Nursing*, **14**(5), pp.594-600.
- Reed, J., Pearson, P., Douglas, B., Swinburne, S. & Wilding, H. (2002) 'Going home from hospital – an appreciative inquiry study', *Health and Social Care in the Community*, **10**(1), pp.36-45.
- Reed, J., Weiner, R. & Cook, G. (2004) 'Partnership research with older people – moving towards making the rhetoric a reality', *International Journal of Older People in Nursing*, **13**(3a), pp.3-10.
- Richardson, L. & Reid, C. (2006) '“I've lost my husband, my house and I need a new knee ... why should I smile?": action research evaluation of a group cognitive behavioural therapy programme for older adults with depression', *Clinical Psychologist*, **10**(2), pp.60-6.

Ritchie, J., Bernard, D., Trede, F., Hill, B. & Squires, B. (2003) 'Using a participatory action research approach as a process for promoting the health of older people', *Health Promotion Journal of Australia*, **14**(1), pp.54-60.

Ross, F., Donovan, S., Brearley, S., Victor, C., Cottee, M., Crowther, P. & Clark, E. (2005) 'Involving older people in research: methodological issues', *Health and Social Care in the Community*, **13**(3), pp.268-75.

Tetley, J., Haynes, L., Hawthorns, M., Odeyemi, J., Skinner, J., Smith, D. & Wilson, V. (2003) 'Older people and research partnerships', *Quality in Ageing – Policy, Practice and Research*, **4**(4), pp.18-23.

Tolson, D., Schofield, I., Booth, J., Kelly, T.B. & James, L. (2006) 'Constructing a new approach to developing evidence-based practice with nurses and older people', *Worldviews on Evidence-Based Nursing*, **3**(2), pp.62-72.

Waterman, H. (1998) 'Embracing ambiguities and valuing ourselves: issues of validity in action research', *Journal of Advanced Nursing*, **28**(1), pp.101-5.

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Avoiding sub-prime lenders: credit unions and their diversification in Wales

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Abstract

Considering the increased role for social policy since 1997 in the area of financial inclusion and the financial crises of Farepak and Northern Rock, this paper explores the role of credit unions in provision of financial services. Drawing upon recent research in Wales, the authors explore the different routes to diversification developed by Welsh credit unions to help financially excluded individuals avoid the use of sub-prime lenders. This analysis of credit union development highlights the lessons to be learnt from each strand of diversification before considering the implications of these findings on the wider, UK, credit union movement.

Keywords: Credit union, financial inclusion, diversification

Introduction

Tackling financial exclusion and improving access to affordable credit have been aims of the Labour government since 1997. In power, the New Labour government has developed a strategy to tackle financial exclusion (H.M. Treasury, 1999) which has included a key role for credit unions (Treasury Select Committee, 2006; H.M. Treasury, 2007). The collapse of Christmas hamper company Farepak and the financial crisis of Northern Rock have highlighted the enduring nature of problems in savings and financial services. Farepak in particular shows how instabilities in global capital can impact upon the most disadvantaged in society (Pomeroy, 2007). This paper explores the interface between credit unions and financial exclusion in Wales, where unions have been heavily supported and promoted by the Assembly Government (Thomas, 2004; Kearton, 2006; Drakeford & Gregory, 2007). We explore the diversification of credit union service strategies and highlight future possibilities for credit unions across the UK.

Prior to this research, a number of studies have explored credit union development more generally. Initially, Jones (1999)

outlined ways in which credit unions could expand membership and move towards self-sustainability. He dealt with the concern that most credit unions remain small and few are actually self-sufficient (many of those that are sustainable being employer based rather than community based unions). More recently, Goth *et al.* (2006) have explored the development of 'fast track' credit unions, thus showing how credit unions can end their reliance on national (and local) government subsidy and become self-sustaining. The research reported here builds on these issues by exploring some practical ways in which Welsh credit unions have pursued self-sustainability through a strategy of service diversification (see Drakeford, 2003, for an account of this approach).

In doing so, credit unions have had to grapple with some fundamental questions about their future. Most Welsh unions have been established as community organisations, powerfully rooted in an ethos of mutuality and focused clearly on the basic business of providing savings and loans services. The challenge for the future has been to retain the essential character of the movement, while doing more to expand its membership and public awareness. The

account which follows concentrates in turn on five different strands in a strategy of service diversification by credit unions which, we conclude, represents the most distinctive characteristic of the Welsh response to this challenge. These strands are: Debt Redemption and Money Advice (DRAMA), instant loans, the Department of Work and Pensions (DWP) Growth Fund, Child Trust Fund (CTF) deposit-taking, and a 'mixed basket' of local initiatives. Each approach is tested here against the goal of achieving long-term credit union sustainability, drawing conclusions, where possible, as to their success or otherwise as a means of expanding membership.

Methodology

In total, nine credit unions took part in our study and 30 interviews were conducted with credit union managers (9), staff (10), Board Members (6), volunteers (4) and one Wales Co-operative Centre representative.

The primary method of gathering data was by audio-taped, semi-structured interview (Rubin & Rubin, 2005). Interviews were designed around themes generated during discussions led by one of the researchers with a number of credit union staff. These themes were aligned with the research aims to form a number of general topics for discussion, while the semi-structured nature allowed the interviewer to follow up on further emerging issues, some of which formed topics of discussion in future interviews. Such an approach provides a valuable tool for obtaining the opinions and exploring the attitudes and experiences of a group of people most closely involved in the contemporary Welsh credit union movement. While interviews were intended to focus on those most closely involved in union decision-making, it is in the nature of credit unions that almost all these individuals are also, themselves, users of the services which unions provide.

Once the interviews had been transcribed, copies were sent to the interviewees so that they could read the recorded interview and check it for accuracy. This was done in an attempt to improve the validity of the research data.

A manual thematic analysis of interview transcripts highlighted key themes emerging from each project, as well as searching for themes which crossed project boundaries. A wide range of observations concerning each theme was then assembled and interrogated in order to develop a commentary which gave due weight to prevailing views and concerns. This analytic approach was applied to each of the five forms of diversification explored in the research and it is to these different practical examples which this paper now turns.

Debt Redemption and Money Advice - DRAMA

For a movement dedicated to assisting those at the margins of financial exclusion, credit unions contain within them a substantial difficulty in reaching out to those most in need. Earlier studies (Drakeford & Sachdev, 2001) report that any new publicity campaign generates an immediate influx of interest from individuals whose circumstances are in crisis. While, in the medium term, credit union membership might lead to an improvement in the level of individual indebtedness, it cannot by definition overcome insuperable barriers to that situation, because such individuals are typically unable to build up even the most modest record of savings. And, in conventional credit union practice, without savings there can be no loans.

In an effort to find a way round this problem, the Coalfields Regeneration Trust (CRT is an organisation dedicated to improving the lives of people living in coalfield communities in Britain) has supported South Wales credit unions to develop the Debt Redemption and Money

Advice scheme. The funding provided by the Trust means that unions are able to make loans without the normal security provided by a savings record, with loans underwritten by the CRT, if repayments do not take place. DRAMA is targeted at individuals who, because of owing money to others, are threatened with the loss of a major social asset such as a utility disconnection, eviction for rent arrears or imprisonment for fine default.

DRAMA operates a dual process whereby the credit union firstly 'buys-out' and reschedules the individual's debt alongside work with money advice services, primarily the Citizens' Advice Bureaux, to carry out a comprehensive review of individual circumstances, thus removing the immediate threat with the aim of establishing long-term stability. Furthermore, DRAMA places an emphasis on building savings at the same time as the loan is being defrayed, so that by the time the loan has been paid off, the individual is able to be a fully participating member of the Credit Union.

The two key distinguishing features of diversification through DRAMA can be identified as follows: firstly, it makes mainstream credit union services available to a particularly disadvantaged group in the population to whom they would otherwise be denied; secondly it brings together a solution to short-term crisis with the prospect of long-term improvement.

Our research suggested that participating credit unions were positive about the potential which the approach possesses for reaching out, and recruiting new members. As one respondent put it:

We wanted to help more people, and those eligible for DRAMA are in the most desperate circumstances. Before DRAMA there was no security against high risk lending, even if people had obtained money advice.

Now, with the scheme in place, the unions were able to bring in:

people who would not have been members previously because they would have had no savings ... offering a lifeline to those people.

Yet a number of practical issues exist in the operation of DRAMA. Firstly, there was variability in the quality of working relationships with money advice organizations. Secondly, staff and volunteer attention could be distracted from normal union activities, leaving people disillusioned with the scheme. Thirdly, while one credit union reported that "we have gathered a few good new members", conversion to full membership could be disappointing: "many of those who have had DRAMA loans have closed accounts when loans have been paid and this is not what the credit union wanted". Finally, the CRT funding of DRAMA, which prevented credit union financial losses, made advertising the scheme problematic. There exists a genuine fear that, in knowing the loan is underwritten, borrowers might not repay the loan. As one respondent explained: "the hardest part was how to advertise DRAMA without going into too much detail, as we couldn't advertise it was underwritten".

Our conclusion is that, in terms of diversification, it seems clear that DRAMA is likely to make a marginal, rather than a central contribution to a strategy of strong growth and future sustainability. A number of intrinsic constraints limit the number of new members which unions recruit in this way. These constraints are inherent in the way the scheme is organised, or the product of wider ambivalences within the movement about developing in this direction. Some respondents, for example, reported anxieties that DRAMA applicants might "come along and take the credit union for a ride". A system was needed, it was suggested, "to make sure that genuine people are getting involved with the credit union, and not

people just looking for a quick, cheap loan”. More positively, interviewees confirmed that, for a relatively small number of people, DRAMA offers a service of high importance and relevance. For those with whom it works successfully, it really does offer the prospect of short-term relief combined with long-term stability.

Instant Loans

Traditional credit union practice requires a fixed period of savings before loans can be provided. Yet this can create a substantial barrier not only to those whose circumstances prevent any form of saving, but also to those who have only a very narrow weekly margin from which savings can be squeezed. A second established credit union practice has exacerbated difficulties for these most struggling savers. Traditionally, credit unions calculate the amount of money which can be borrowed as a multiple of an individual’s shares – for example a ratio of 1:2 would lead £50 in savings to a maximum loan of £100. This has created additional problems for those with low savings ability in dealing with unexpected – or “lumpy” – expenditure, such as replacing a broken washing machine, through the credit union.

The situation has generated recent debate within the credit union movement, focused on the provision of instant loans, available immediately on membership. Instant loans are a form of ‘capacity lending’ – that is to say eligibility is assessed not on prior savings, but ability to repay. This draws more on commercial financial techniques, another departure from traditional practice. Of the different forms of diversification discussed in this paper, instant loans and capacity lending have gradually become one of the most widely accepted new services: partly because capacity lending can assist existing members with low savings, as well as being attractive to new members. Provided they are assessed as being able to repay, such members are now able to access

larger loans than from credit unions operating a traditional multiple of savings policy.

In the accounts offered by our respondents, the decision to move to instant loans was accelerated through their involvement with an advice and training session offered by the commercial sector. This introduces credit unions to instant loan provision based on capacity lending which increased both business and help for the community. As was explained to us, this system “won’t hurt the people who don’t have the ability to pay it back”. The Treasury Select Committee (2006, p.26) also reported how this training had lowered loan delinquency and operating expenses whilst increasing both assets and membership. Furthermore, respondents emphasised that learning from the commercial sector was a supplement to, rather than a substitute for, established credit union activity.

Credit unions listed a number of advantages in the provision of instant loans. Firstly, they allow unions to compete directly with sub-prime, high-cost instant lenders:

Having access to instant loans is hopefully stopping them from going to high cost lenders where a big chunk of their basic money is paid in interest ... helping socially excluded people move away from the lenders who tend to charge more.

Highlighting this point, the Treasury Select Committee (2006, p.13) investigation provided a set of up-to-date calculations of interest rates charged in the sub-prime sector, quoting an APR range of 140–400% for recognised home credit companies, and an estimate rate of over 1000% for illegal or unlicensed lenders. By contrast, instant loan credit unions make use of a new ability, provided through the Credit Union (Maximum Interest Rate on Loans) Order 2006 to increase the maximum rate of

interest which a credit union can charge on loans from 1% to 2% per month.

Secondly, respondents emphasised that instant loans also allowed credit unions to position themselves in a way which created real market difference and distinctiveness in relation to high street banks. The Treasury Select Committee (2006, p.14) quotes evidence from the HSBC to the effect that, for mainstream banks:

provision of short-term, very low value micro-credit is simply not deliverable in a cost-effective manner. To cover our operating costs alone would require charging a disproportionately high APR.

In our research, instant loans were made for exactly such micro-credit purposes, identified as “telephone bills where you can expect the loan to be paid off in three months time, ready for the next one, or Christmas or holidays, where again loans can be expected to be paid off in 12 months time”. This reflects the typically small nature of loans required by those excluded from financial services (Whyley, 2003; HM Treasury, 2004).

Thirdly, provision of instant loans, through capacity lending, served to erode a distinction between ‘ordinary’ members and ‘instant loan’ users in some important ways. One respondent put this negatively: “one downside was finding out how much debt current members were already in, although they had been good at paying back, they were borrowing money to pay debt.” Put positively, however, this suggests that instant loan applicants were not, necessarily, more likely to default than members recruited in the traditional way. Thus, for some, capacity-based lending had, in important ways, narrowed the perceived gap between different sorts of loan applicants, rather than widening it, as some had feared. The effect of instant loans was integrative, illuminating rather than obscuring ‘common’ bonds between members.

Department of Work and Pensions Growth Fund

Credit unions which have developed instant loans are those able to do so from their own resources. The union must have sufficient funds in savings, and a willingness to take on additional risk, if it is to embark on this form of diversification. Recognising that many unions are not in such a position, the DWP, as part of the Westminster Government’s financial inclusion strategy, has provided new funding to help credit unions offer instant loan facilities. A sum of £36 million has been made available, through the DWP’s Growth Fund, to promote the work of third sector lenders, including credit unions. The scheme works by offering low cost loans to low income individuals in areas of high financial exclusion. The Fund targets people on low incomes currently defined as £123 a week or less for a single person; up to £215 a week for a lone parent with two children; and up to £400 a week for a household with four children. This ensures a reduction in the cost of loan repayments for excluded people in comparison with high cost, alternative lenders, while retaining the value of each loan fund for the long-term benefit of the community.

In order to have access to the Growth Fund, unions have to demonstrate a capacity to administer instant loans to a national standard. While there was an off-putting element to this – “there was a lot of time and effort required to get it all set up, and there was some reluctance from the Board at all the work involved” - for what remains an essentially local movement this was, for some respondents, an important “opportunity to be a partner in a bigger world than our own”.

In practical terms, as with instant loans, the major point made by those of our respondents who most clearly supported participation in the DWP Growth Fund was that, for individual users, the choice is not

between such a loan from a credit union and no loan at all, but between a credit union loan and a loan from a door-step lender:

our main reason [for taking part in the DWP scheme] is that it is a wide fund of money which we can use to target high risk potential members with instant loans ... [if] we have to say, 'sorry we don't do instant loans' they would then go to the Provident at the end of the street. ... It will be difficult to actually compete fully with doorstep lenders as they go door-to-door. But it will allow the credit union to enter into areas which we do not penetrate at the moment.

For unions, and individuals, with this orientation there is no basic contradiction between offering Growth Fund loans and more traditional credit union practice. The link, as one respondent put it, is as much moral as financial:

Credit unions exist to help certain groups in the community – groups, perhaps, a segment below those we are currently serving, groups we haven't been able to deliver a service to, or reach out to, so far. ... This credit union has a strong moral feeling ... and we saw this scheme as an opportunity to help that segment of the community.

Our conclusion is that the DWP Growth Fund offers one of the best opportunities for sustainable expansion but one which relies on a fundamental reorientation in traditional credit union thinking. Historically, the default position of previous, credit union loan-making practice has been to place the onus on the applicant to make a persuasive case because, as we were regularly reminded, the risk falls on the savings of other members. Instant loans and DWP loans reverse that position, so that the default position becomes agreeing a loan unless a good reason can be discovered as to why that should not be the case. This shift in

thinking will take time to become embedded in credit union practice.

The early evidence we collected gives some ground for optimism. The most thoughtful responses in our research seem to come from those who have moved beyond a position in which unions are regarded as having to choose between a traditional ethos and a new business orientation. A fresh synthesis is emerging, in some places, where the essential purposes and practices of credit unions are retained but applied in new ways. At root, this is about finding effective ways of responding to contemporary conditions. As one respondent put it:

unless a credit union can develop products and services to reach these parts of the communities, these financially excluded parts of the community, we will have failed. ... Any credit union which has policies and products that will drive people to doorstep lenders is flawed.

Child Trust Fund - CTF

Thus far, three loan developments have been explored, yet the foundation of the movement is based on savings – for low income members the saving mechanisms are the most valued aspect of membership (Berthoud & Hinton, 1989). The first of the four obligations of unions laid down by the Credit Union Act of 1979 is “the promotion of thrift amongst members by the accumulation of their savings”. Our respondents continue to believe that this aspect remains central to the services of credit unions, pointing to recent evidence (Financial Services Authority, 2006; Lister, 2006) of the very low level of savings in the poorest UK communities. Furthermore, the Treasury Select Committee (2006, p.3) highlights the importance that even a small amount of savings can have on the personal finances of those on low incomes. This becomes particularly important for credit

unions who provide services in areas where mainstream financial institutions fail to provide facilities and products convenient for those with limited or no saving capacity (Speak & Graham, 2000; Drakeford & Sachdev, 2001).

An experimental scheme run by the Welsh Assembly Government has attempted to forge links between credit unions and one saving mechanism, the Child Trust Fund (CTF). The CTF is the Westminster Government's 'baby bond' scheme, essentially a mechanism to develop the savings habit and provide an asset for all young people when they become eighteen years old. An initial £250 is paid by the Government for every child born from September 2002 with an additional £250 going to children in households in receipt of maximum Child Tax Credit. This payment arrives as a voucher to be invested by the parent into an account of their choice. Parents and family can add up to £1,200 annually to the account, in a tax efficient manner. Moreover, the Westminster Government will top-up accounts when children reach seven and thirteen years of age while, in Wales, the Assembly Government will provide its own additional top up of £50 to all children starting school (in Wales), with £100 for the most disadvantaged children (Welsh Assembly Government, 2007).

The Welsh Assembly Government demonstration project assists credit unions in attracting deposits to the non-stakeholder, deposit/savings account which unions can provide. It is clear from our respondents that, without the financial support of the Assembly, the initiative would not have been possible:

we were offered funding to be a demonstration project. Without the costs being covered, credit unions cannot afford to do experimental things because they are a high risk business and rely heavily on volunteers.

Or, as another respondent put it: "it might have been possible for the credit union to run the scheme further on down the line, but we wouldn't be doing it now without the funding".

It is too early at present to determine the full effect of this diversification strategy and our conclusions are therefore tentative. At present, activity has focused on information-giving and consciousness raising which has involved a range of places, projects and professionals – parent and toddler groups, pre-school groups, family and community centres, surgeries, anti-natal groups and midwives, as well as local shops specialising in baby clothing and equipment. As a basic contextual factor, however, it is important to echo the conclusion drawn by the Treasury Select Committee (2006, p.48) that "saving is not accorded the same priority in the Government's strategy for promoting financial inclusion, as credit, advice and banking". Some of the same imbalance can be detected in the range of initiatives reported here, with the CTF standing out as the only example to fall firmly on the savings side. Yet credit unions are well placed, we would argue, to address this tension, because of the way in which, in their own terms, they place equal weight on making saving easier and providing affordable credit.

For credit unions themselves, there is evidence which suggests that CTF accounts could offer a substantial source of un-tapped assets to credit unions. Such accounts are least likely to be opened in areas where credit unions are most active, and the links between the ethos and purpose of the credit union movement and asset-based welfare are readily apparent (see Gregory & Drakeford, 2006). Once an account is open, any funds deposited in it are available for lending purposes over an eighteen year period. At the same time, many respondents, across the whole range of different diversification initiatives, have emphasised to us that the long-term future for credit

unions has to lie in ‘normalisation’ – that is to say, in making credit union membership as taken-for-granted as any other form of financial institution. In that regard, the Child Trust Fund does, indeed, offer a chance to bring a whole generation into credit union participation, from their very earliest days. One of the unions already had a substantial investment in building up its presence in schools, through junior savers clubs and other initiatives. For them, the CTF project offered some natural affinities with that work: “hopefully now, by offering Child Trust Fund accounts we can teach the children to save ... then we’ll have all these children coming through knowing a credit union”.

The key practical advantage which credit unions were thought to have in the minds of potential depositors was their local presence and personal approach:

the credit union is local and more approachable and this is important because some people don’t trust banks. And a lot of the areas the credit union is dealing with are the more deprived areas where people are financially excluded and to them we are more approachable and more normal.

In both participating unions, the point was made by respondents that, in publicising the CTF, the project was also drawing attention to credit union services more generally. For many people contacted, the information was the first time they had heard both of credit unions and the CTF. There was some early evidence of people joining the credit union as a result, independent of any decision about CTF depositing. Respondents were aware of some of the wider benefits which unions could derive from taking CTF deposits:

obviously we are allowed to use the money deposited in Child Trust Fund accounts for our day-to-day business, so that gives us more money to be able to

loan out and, of course, the more money we get out the more money we get back in interest, so our income goes up.

Even at this early stage, however, some difficulties and drawbacks were apparent. National figures demonstrate that rates of deposit are heavily skewed by social class (HMRC, 2007) and credit unions face the same difficulties as all other attempts to persuade individuals in difficult and volatile circumstances to give priority to an issue which has long-term benefits, but little immediate impact on their circumstances. Not only are original vouchers, once deposited, locked away for an eighteen year period, but any additional savings which might be added to that account are similarly unavailable thereafter. There were some anxieties, too, about the ability of a credit union account to compete in the market place: “we can offer only two and a quarter percent in interest, whereas the high street banks are offering twice that rate.”

To conclude: there is a sense in which, in bringing together credit unions and the CTF, two relatively unknown players in the financial world are being combined. For individuals who have little experience in this area, and for whom finances are a daily struggle, the fear of commitment to untested (to them) organisations is especially pressing. It may be that the effort needed to counteract this feeling will be exacerbated in the case of the CTF initiative where individuals are being convinced both to join the credit union (of which they may know little) and to engage with the CTF (of which they may know less).

Mixed Basket

In preparing for the research reported here, and conducting preliminary inquiries into the pattern of credit union diversification in Wales, it soon became clear that, while there are a number of very specific routes to expansion (as discussed in earlier sections), there are also credit unions which rely on a

less concentrated approach or, as one respondent put it to us, as “not having tunnel vision”. In some cases, this amounts to a concerted attempt to develop a wide range of individual initiatives, each one by themselves more modest than others already considered but, cumulatively, amounting to a separate and distinctive diversification strategy, deliberately relying on breadth, rather than depth as its main motivating principle, and aiming to provide a range of new services attractive to different groups in the local population.

We cannot, here, list all the individual initiatives which fall within this approach. They include discounts for credit union members at local stores and services; reduced membership rates at a local leisure centre; loans to young people in order to cover the rent of a scooter needed to access employment; Home Improvement loans and payroll deduction through a partnership with the local authority; funeral insurance, to provide low-cost funeral cover for members; ‘savings circles’ or Christmas savings clubs, where members purchase vouchers to be cashed for goods in the future, and Western Union Money Transfers, a scheme which allows groups of workers such as Filipino nurses, and others with a tradition of remitting money to families in ‘home’ locations, to use the credit union for such purposes.

Perhaps the most striking finding from our investigation of the ‘mixed basket’ approach is the way in which it relies on a whole series of bilateral relationships with other organisations. Initiatives reported to us relied on partnerships, or at least close contacts, with organisations as diverse as the local authority, central government departments, local traders, insurance companies, the Local Health Board, the police, specific professional groups and the Wales Co-operative Centre. Such partnerships can be especially valuable in the hardest, early months of establishing a new initiative. Sometimes that assistance

comes in the form of direct financial underwriting, so that new projects can be attempted without risk to the assets of existing members. Other forms of assistance also emerge from working in this widely networked way, ranging from the highly tangible and practical (other organisations taking responsibility for producing and disseminating leaflets, for example) to the less direct but, nevertheless, important way in which working with others both validates credit union membership and provides what one of our respondents called, “real penetration in the community”.

Unsurprisingly, this strategy does not rely on any single strand providing rapid growth. Indeed, in most of the different schemes outlined above, respondents were keen to emphasise the gradual and organic way in which new members were recruited – “you have to be happy with slow growth”, was a regular theme. Unlike single strand strategies, where slow growth can be a source of considerable anxiety, it could be argued that the ‘mixed basket’ approach works *with* the grain of UK credit union development, relying on a steady, rather than spectacular attraction of new members which, cumulatively, amounts to sustainability.

A further finding suggests that, while the ‘mixed basket’ approach relies on a plethora of specific initiatives, there are real prospects of, and advantages in, linking different initiatives into a wider package of services for the individual member: “you have to provide the whole service; that is how you really get people involved”. This was especially reported to be the case in relation to groups who are otherwise even more difficult to reach than those in general financial exclusion. Corporate leisure centre membership, which provides unlimited use of gym and swim facilities for an annual sum of £110, for example, was reported as especially useful in attracting young members:

there are young boys, seventeen, eighteen year olds who join for this and would never have joined the credit union before, and who save a couple of pounds a week, so that is brilliant, absolutely brilliant.

Equally, providing a money transfer facility allows the credit union to become newly relevant to some minority ethnic populations.

A multiple initiative approach also provides some additional possibility for what one respondent called ‘rejuvenation’ of the union. As well as new members themselves, new projects draw in a new range of contacts and provide a fresh stimulus to those already committed to union activity. The result is a sense of momentum, and of renewal.

The downsides of this approach highlighted in our interviews, included the way in which this strategy is highly demanding of staff and volunteers, both in terms of the intellectual challenge of continual innovation – or “dreaming up these projects”, as it was put to us - and in terms of time and effort needed to keep track of each strand of union activity, and to keep those different strands on track. Partnership working, as is well attested elsewhere, had enormous advantages over the long-term, but can be highly intensive, in terms of the energy and effort devoted to building and maintaining the relationships on which partnerships depend. For some of our respondents, there was a sense of looking forward to “a bit of a break before working on the next scheme” – even as a set of new schemes were being suggested!

A second issue which arises in this approach is the way in which unions have to face, continually, the challenge of investing in new initiatives, in advance of the fruits beginning to emerge. “The first few months are the toughest”, is a theme which might be echoed by many of the unions reported upon

in this research but, for a ‘mixed basket’ union, this is a factor which has to be faced time and again, as each new initiative emerges and the attempt is made to put it into practice.

Conclusion

This paper has concentrated on a strategy for credit union development in Wales which, in another context, was once described as a “dash for growth”. The nature of the change which underlies this strategy has implications across the UK.

Firstly, we conclude that development of credit unions which depends upon competing with mainstream financial services, shaking off the past in favour of a very different future, is both unnecessary and unlikely to be successful. The evidence presented here demonstrates that diversification and expansion can be achieved in a way which remains consistent with the enduring ethical basis of the credit union movement: the ‘provident purpose’ of union activity, democratic ownership and wider community purpose of their schemes – these remain the motivating purposes which draw volunteers and users into membership. The greatest safeguard against an undermining commercialisation, or a future in which credit unions achieve sustainability by turning their backs on those who need their help the most, remains the vigour with which these issues are debated here in Wales, and beyond.

Our second conclusion is that, for diversification to secure growth and sustainability, unions cannot rely on a single ‘big bang’ development. Rather, diversity has to be accepted as a key strength. It provides a strategy for both *products* – new forms of loans, new forms of savings – and for *promotion* – leaflets, talks, posters, newspaper articles, door-to-door campaigns and, still the most successful of all, word-of-mouth recommendation.

These are conclusions which hold good not only for Wales, but for the British credit union movement. Through their flexibility and community connections, credit unions can contribute to a fuller and more robust financial inclusion strategy, one which combines a focus on affordable credit with accessible savings, and one which has, as its core aim, the provision of services to those for whom mainstream financial institutions have only a demonstrated record of market failure.

References

- Berthoud, R. & Hinton, T. (1989) *Credit Unions in the United Kingdom*. London: Policy Studies Institute.
- Drakeford, M. & Sachdev D. (2001) 'Financial exclusion and debt redemption', *Critical Social Policy*, **21**(2), pp.209-30.
- Drakeford, M. (2003) 'Coordinating policies and powers to reduce social exclusion: the Welsh approach', *Wales Law Journal*, **1**(3), pp.245-255.
- Drakeford, M. & Gregory, L. (2007) 'Sleeping Giants: Unlocking the Potential of Credit Unions in Wales', working paper 97. Published by Cardiff School of Social Sciences, Cardiff University, at <http://www.cf.ac.uk/socsi/research/publications/workingpapers/index.html>.
- Financial Services Authority (2006) *Levels of Financial Capability in the UK: Results of a Baseline Survey*, London: Stationery Office.
- Goth, P., McKillop, D. & Ferguson, C. (2006) *Building Better Credit Unions*, Bristol: The Policy Press.
- Gregory, L. & Drakeford, M. (2006) Social work, asset-based welfare and the Child Trust Fund, *British Journal of Social Work*, **36**(1), pp.149-57.
- H.M. Revenue & Customs (2007) *Child Trust Fund Annual Report*, London: H.M. Revenue and Customs.
- H.M. Treasury (1999) *Access to Financial Services*, London: HM Treasury.
- H.M. Treasury (2004) *Promoting Financial Inclusion*, London: HM Treasury.
- H.M. Treasury (2007) *Review of the GB Co-operative and Credit Union Legislation: A Consultation*, London: HM Treasury.
- House of Commons Treasury Select Committee (2006) *Financial Inclusion: Credit, Savings, Advice and Insurance*, HC 848-1, London: Stationery Office.
- Jones, P. (1999) *Towards Sustainable Credit Union Development: ABCUL*.
- Kearton, L. (2006) *Credit Union Roundtable Summary Report*, Cardiff: Welsh Consumer Council.
- Lister, R. (2006) 'Poverty, Material Insecurity and Income Vulnerability: The Role of Savings', in Sodha, S. & Lister, R. (eds.) *The Savings Gateway: From Principle to Practice*, IPPR: London, pp.8-33.
- Pomeroy, B. (2007) *Review of Christmas Savings Schemes*, London: HM Treasury.
- Rubin, H. & Rubin, I. (2005) *Qualitative Interviewing: The Art of Hearing Data*, Thousand Oaks, C.A.: Sage.
- Speak, S. & Graham, S. (2000) *Service Not Included: Social Implications of Private Sector Restructuring in Marginalized Neighbourhoods*, Bristol: Policy Press.
- Thomas, S. (2004) *Making the Money Go Around: An Overview of Credit Union in Wales*, Cardiff: Welsh Consumer Council.

Welsh Assembly Government (2007) *One Wales: A Progressive Agenda for the Government of Wales*, Cardiff: Welsh Assembly Government.

Whyley, C. (2003) *Credit Use in Wales*, Cardiff: Welsh Consumer Council.

Notes on Contributors

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Book Reviews

Negotiating Death in Contemporary Health and Social Care

Holloway, M.

Bristol: Policy Press, 2007, pp.216,

ISBN: 9781861347220, £19.99, (pbk.)

This is an impressive, wide-ranging book which surveys the relevant theoretical perspectives and puts the practice issues into their social and policy contexts. The objective is to enrich working practice because our 'beliefs and practices surrounding death and dying are in a state of flux' (p.145). The eight chapters cover seven broad topics: death in late modernity; the delivery of health and social care; theories of dying and bereavement, including social anthropology, philosophy and theology; contemporary debates about dying; dying and bereavement in old age; the aftermath of death; and the need to integrate theory and practice. There is an illuminating sequence of case studies and good use of tables, figures, and reflective practice questions.

Two interlocking concepts prove important. The first is that of 'liminality'. Much of the ritual we have inherited – liturgy, sealing tombs, secondary burial, and the like – concerned the fate and well-being of the dead person, and governed their transition after biological death. Now the liminal state that primarily concerns us is the one *before* death, where medical technology is such that "many seriously ill people are neither (by any easy consensus) quite 'alive' nor quite 'dead'" (Kellehear, 2007, p.784).

The second is the altered status of the dead person within our secularised, personalised funeral ceremonies. Despite the 'revival of death' in the 1980s and a renewal of popular interest in ritual and symbolism, contemporary practice is psychologically focused on the emotions of the bereaved. Holloway makes a case for staff being better

prepared to deal with concerns and distress about life's meaning. She regrets the retreat from pastoral theology, referencing practitioners who try to respond to 'spiritual pain' among the dying and bereaved. To a radical secularist, our fate after death is not a concern, but Holloway quotes Ros Coward's view that the older rituals offered something more cathartic, and supportive of grieving. Ken Howse questions the causal stories linking well-being in later life with religious belief, pointing out that, if they were correct, "institutional religion constitutes a kind of cultural resource that we may find ... hard to replace" (2004, p.19). Young and Cullen (1996) assert the need to achieve a richer balance and better orientation between the personal and the communal.

As a former social worker, Holloway continues to value Colin Murray Parkes' model of bereavement as a 'psycho-social transition' and would enhance its sociological and psychological components with a third existential dimension. Attachment theory has had to modify some assumptions in the face of a challenge from 'continuing bonds' theory and Holloway highlights the relevance of memorialising the dead to bereaved parents and to people from some faith traditions. There are useful sections on the globalisation of death; the shifting boundaries between public and private; and on cultural pluralism. If only partially successful in looking beyond the UK, Holloway offers valuable vignettes, for example, the growth of secondary burial to communal plots in Japan as ancestor worship has declined; the development of an African palliative care network in response to AIDS; the discomfort of some African-Americans as more personalised ceremonies displace the commemoration of historical suffering. Holloway's own recent work contrasts the changing experience of Chinese communities in Hong Kong and

abroad. The book is stimulating regarding euthanasia and assisted dying, with a helpful exposition of the terminology. I was interested by her sceptical appraisal of advance directives.

Turning to the experience of the old, Holloway says trenchantly of recent policy in the UK: “the emphasis on quality of life has not included the idea of moving towards death” (p.121). The list of issues is relentless: the higher risk of suicide; the under-representation of users of palliative care (even among people with cancer); the privileging of exceptional death; the lack of qualitative research; the prevalence of death in hospital (often on general wards) and in nursing homes. These issues are exacerbated by a continuing professional reluctance to address the fact of death itself and help the patient acknowledge their “dying phase of life” (pp.122-5).

Holloway sees potential for the current UK policy frameworks to correct the more destructive aspects of the managerialism that followed the NHS and Community Care Act. Palliative care approaches need to be diffused widely across health and social care. “Holistic practice” is the key that will “respond with knowledge, competence and sensitivity” and privilege “the richness of the interdisciplinary encounter” (p.182). She is frank about the obstacles to pursuing such an agenda - as her excellent exposition of the idea of ‘a good death’ shows, palliative care does not lend itself to objective evaluation. She quotes Overtveit (1993) on the need for a shared primary goal in successful inter-disciplinary practice but, if her project is to succeed, she has understated the need for strong, consensual leadership. How else to reconcile inter-disciplinary tensions, maintain an accepted ideological over-view and manage the meaningful input of service-users?

I hope this book will be widely read and that some of its overtly expressive themes are taken up at policy level.

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References:

Howse, K. (2004) ‘Religion and spirituality in later life’, *Generations Review*, **14**(4), pp.16-8.

Kellehear, A. (2007) Book Review: Kaufman S.R. (2005) ‘How Hospitals Shape the End of Life’, *Ageing and Society*, **27**(5), pp.783-5.

Overtveit, J. (1993) *Coordinating Community Care: Multidisciplinary Teams and Care Management*, Buckingham: Open University Press.

Young, M. & Cullen, L. (1996) *A Good Death. Conversations with East Londoners*, London: Routledge.

Service User and Carer Involvement: Beyond Good Intentions

McPhail, M. (ed.)

Edinburgh: Dunedin Academic Press, 2008, pp.96, ISBN: 1-903765-63-3, £13.50 (pbk.)

This book aims to cover how service user and carer involvement has been implemented in both Scottish universities and across the Scottish health and social care sectors. However, it goes further and presents a rich and comprehensive story that provides an interesting contribution to the debate on service user and carer involvement in health and social care.

Chapter One provides an overview and sets out a challenging call that service user and carer involvement can no longer be tokenistic and must go ‘beyond good intentions’. Chapter Two lays out a conceptual framework to the book. It contrasts two broad types of approach to involvement. Firstly, there is the ‘managerial’ or ‘consumerist’ approach with its ‘top-down’ imposition of targets and policies for the introduction of service user and carer involvement in health and social care. In contrast, there is the more ‘bottom-up’ democratic model that has developed from ‘user-led’ organisations which is based

on the principle of the social model of disability. It is argued that one is the “consumerist, managerial” agenda of governments, the other is the agenda of various civil rights and social movements” (p.8). Chapter Two also sets out both the policy context of Scottish social work, and of user and carer involvement in English and Scottish universities.

Chapter Three tells the successful story of the CU group of service users and carers that ‘grew’ at the University of Dundee and the lessons that can be learnt from their experience. This is coupled with the experience, at a wider level, of developing a Scottish network to support service user and carer involvement across Scottish University social work departments. Chapter Four is written by a carer and tells the powerful story of her personal experience of caring for her son and of her experiences of involvement at the University of Dundee as a carer consultant with the Scottish Institute of Excellence in Social Work Education project. Chapter Five is written by a service user who is a member of the CU group at Dundee University. With both force and humour, he reminds us that involvement cannot be tokenistic and must be real involvement that is about re-distributing power and partnership working.

Chapter Six focuses on ‘Ways of Knowing’, looking at evidence-based practice and the importance of listening to the service user/carer perspective of knowledge and understanding. The example is given of the ‘Making Sense of the Caring Experience’ module on the MA course at the University of Dundee. Here, students spend significant time with service users or carers trying to understand and experience their lives. This gives students a different perspective of knowing. The second example is an interesting look at the experiences of people with personality disorder and the potential for service user knowledge to inform health and social care practices.

Chapter Seven focuses on two themes which run through the book. The first is the frustrations around user involvement, “which stem from the failure and, occasionally, unwillingness of professionals and policy-makers to hear what service users and carers are saying” (p.72). The second is the potential of user and carer involvement, “the possibility of reconstructing professional practice, social work and social care services, and professional education, on a very different basis” (p.72). The chapter concludes by emphasising the importance of demonstrating trust and awareness of power differentials when trying to implement service user and carer involvement in health and social care.

For me, as a service user, researcher and academic, this was an interesting and innovative book. I could identify with the longing and desire to increase and develop service user involvement that is so evident in the passion of the book. The academic arguments made sense and were interesting, leaving me wanting to read more. An enjoyable, passionate and gripping read!

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Using the Law in Social Work (3rd edition)

Johns, R.

*Exeter: Learning Matters, 2007, pp.176,
ISBN: 1-84445-134-2, £15.00 (pbk.)*

It is not surprising that this book has made it to a third edition. Not just because the law affecting the day-to-day practice of social workers continues to change rapidly, but because there is a growing need for a text that is accessible to students who enter their training often with limited knowledge of what used to be called the British constitution. A basic text prepares students

for books that go into greater detail and serves as a quick catch up for those of us whose knowledge is partial or somewhat historical.

This edition starts with a discussion of human rights before moving to areas of law covering children, adults and youth justice. The latter has an engaging set of case studies, perhaps in acknowledgment that many social workers in England and Wales do not have so great a familiarity with this area as their counterparts in Scotland where the social work profession has much greater contact with the criminal justice system. Court processes and powers are also covered. For me, the activities were less precise and reflective than they promised at first and I would be interested to see if this area could be developed further for any new edition. Legal changes in relation to research governance and ethics might also be worth considering for a future text, since frontline social workers may be at the receiving end of requests to consider these issues more than they have in the past, let alone having greater encouragement and opportunities to carry out research themselves.

The book offers some guides to current legal changes that must be the bane of any textbook writer on the subject. The protracted reform of mental health legislation in England and Wales must have been frustrating and Johns offers some guidance here but inevitably this is limited. Developments in respect of personalisation will also give rise to legal questions for frontline practitioners, despite the moves to reduce care management activities in setting up and in monitoring this aspect of social care.

For researchers, this book would be a good refresher when undertaking studies that cover practice activities and decision making. The index is helpful and the citations are easy to follow. There is a long and honourable tradition of the study of

social work law and its implementation. If we wish to sustain this then, as researchers, we are well advised to know what we are talking about.

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Direct Payments and the Personalisation of Care

Pearson, C. (ed.)

Edinburgh: Dunedin Academic Press,
pp.84, ISBN 9781903765623, £12.95 (pbk.)

We live in a time of strange paradoxes. Nowhere are these more evident than in the area of direct payments and the personalisation of care. A policy promoted by the most militant disability movement in history was taken up and implemented by a right-wing Conservative government in the 1990s and now, under a New Labour government committed to neo-liberal policies, is increasingly promoted as the model for all adult care services. The policy is hailed by activists as the most empowering development ever seen in the sphere of disability and opposed by public sector trade unionists as a Trojan horse for privatisation. A degree of confusion and disorientation is therefore understandable.

This edited collection by Charlotte Pearson provides a useful guide through this ideological fog of competing policy discourses. It draws on a range of research produced over recent years, including a two-year, UK-wide study of direct payments conducted by Pearson and her colleagues and funded by the ESRC. Its focus is primarily on the Scottish aspects of that study, though some comparisons are made with the wider UK context.

Chapter One by Pearson and Riddell traces the development of direct payments in Scotland, from their patchy beginnings in the independent living initiatives of the mid-

1990s through to the mandatory duty placed on local authorities in 2003 to offer direct payments to all eligible groups. Despite that duty, the uptake of these payments continues to be uneven. The reluctance of Scottish local authorities to promote direct payments as a mainstream option is the focus of Chapter Two. A comparison of the practice of two different authorities highlights some of the factors – organisational, practical, ideological – which affect their take-up. In local authority 1, covering a large rural area, direct payments were integrated into the community care system, allowing social workers greater flexibility to make use of the payments where appropriate. By contrast, in local authority 2, which covered a large urban area with significant deprivation, the direct payments budget was ring-fenced, leading to waiting lists for those eligible for payments. The issue here, however, is not simply a conservative resistance to ‘modernisation’ on the part of councillors and social workers. As Pearson notes, workers in *both* authorities raised concerns about the potential impact of an extension of direct payment schemes on existing services. The issue is a very real one. Hundreds of day centre workers in Glasgow, supported by carers’ organisations, have just returned to work (December 2007) after a bitter 8-week long official strike against substantial pay cuts and the planned closure of several day centres. These resulted from Glasgow City Council’s proposals for the ‘personalisation’ of services for people with learning disabilities. Other factors affecting social workers’ involvement in direct payment schemes include training (or lack of it) and the additional paperwork which they involve.

As Chapter Three shows, one factor which has had a significant impact on take-up is the existence or otherwise of support organisations, providing information and advice in areas such as the hiring of personal assistants. However, while in the

early days of direct payments these were often user-led and rooted in the principles of independent living, increasingly support is provided by non user-led organisations that often do not share this wider vision. The weak funding base of many local support organisations and the extension of direct payment schemes across a much wider range of adult care groups suggest that the earlier model of support may soon be supplanted by a more commercial approach, particularly in areas such as the employment of personal assistants and payroll management (and Pearson notes the growing interest of local businesses in these areas).

In Chapter Four, Riddell continues the discussion of the factors affecting the take-up of direct payments, with a greater focus on the ideological issues involved. The fact that the demand for direct payments resulted from disabled people’s experience of State-provided services as oppressive leads her to suggest that the Left needs to avoid blanket criticisms of these schemes. Certainly, Victoria Williams’ chapter on the views and experiences of direct payment users, while based on a very small sample, confirms the findings of other research that many service users enjoy the greater flexibility, choice and control which direct payments provide. That said, for carers in particular, direct payments were often a service of last resort while several service user respondents struggled with issues of administration, paperwork and the retention of personal assistants.

In her final chapter on the future of direct payments in Scotland, Pearson notes the concern expressed by Barnes and Mercer that these payments are being used “as part of a cash-limited social care market, rather than a means to facilitate independent living” (p.64). This is a genuine fear and one which is shared by many public sector trade unionists, including social workers. It highlights the need to create forums where, together, we can develop models of service

which reflect the real needs and wishes of service users, rather than their purchasing power. This book is a helpful contribution to that process.

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Understanding Social Work Research

McLaughlin, H.
London: Sage Publications, 2007, pp.186,
ISBN: 10 1-4129-0849-3, £19.99 (pbk.)

This useful and comprehensive book looks at the role and value of social work research. It recognises that understanding research is an important task both for students training for qualification into social work and for qualified social workers.

The author begins by suggesting that, once they have qualified, few social workers are able to pay much attention to social work theory, research or literature, because they need to adopt the 'real world' culture of their new employers and colleagues.

In ten chapters, the author shows how social work practice can be improved by research-mindedness. McLaughlin begins by exploring why research is critical to the development and survival of social work. This discussion locates research in the social and legal contexts of the real world within which practice operates.

The book attempts to show that research is not just undertaken for the sake of academic knowledge. McLaughlin argues that it is important for research to be written for practitioners as well as academics, and that knowledge needs to be translated into ways of working that support social work practice.

The author then explores the philosophical, epistemological and ontological

underpinnings of social work research - linking each of these standpoints to different research methods. In looking at the ethical basis of social work research, McLaughlin cautions that:

It should also be remembered that gaining ethical committee/research governance committee approval does not mean the researcher can stop thinking ethically. (p.57)

The following broad themes are covered: evidence-based practice (currently an important plank of government policy); the new orthodoxies developing from the modernisation agenda; the importance placed on involving service users in social work research; anti-oppressive practice and anti-discriminatory practice; immigration and asylum; and interdisciplinary working. A critical approach is urged in looking at both the advantages and disadvantages of these developments.

Overall, this is a book that contributes to the use of research as a tool for social workers. It is well-organised with relevant sections that include reflexive questions that will be helpful for social work students at both qualifying and post-qualifying levels. It could be included in almost any social work programme as recommended background reading. It would help practitioners engage with debates about the application of research in practice. It also gives a brief introduction to those wanting to begin to learn about carrying out research.

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