

The public health role of learning disability nurses: a review of the literature

Kay Mafuba explores how learning disability nurses contribute to the implementation of public health policy for people with learning disabilities

Summary

Kay Mafuba examines the literature on learning disability nurses' role in public health. She identifies methodological shortcomings and highlights gaps in knowledge concerning nurses' implementation of national policy and the experiences of people with learning disabilities in accessing public health services.

Keywords

Literature review, policy implementation, public health

IN THE UK there is a disparity between the health of people with learning disabilities and that of the general population, and between health care for those with learning disabilities and those without (Kerr 2004). People with learning disabilities experience poor access to health care (Department of Health (DH) 1999a, 2001, 2006a, 2007a, Disability Rights Commission (DRC) 2006) and are known to have much greater health need (NHS Executive 1998, DH 1999b, Cancer Research UK 2008). People with learning disabilities experience unequal access to health services (Kerr 2004, DRC 2006) and inadequate diagnosis of treatable conditions. Furthermore, they are more likely to die from preventable causes (Hollins *et al* 1998, Mencap 2007, DH 2007a,b). International studies have also shown poor uptake of public health initiatives by people with learning disabilities (Beange *et al* 1995, Beange and Bauman 1990, Jacobson *et al* 1989, Howells 1986, Wilson and Haire 1990, Kerr *et al* 1996, Jones and Kerr 1997, Stein and Allen 1999).

The workforce responsible for ensuring that UK public health policy frameworks are implemented is dispersed across various organisations (Wanless 2004). *Facing the Facts* (DH 1999b) noted confusion and a lack of clarity in relation to responsibilities and roles in health care for people with learning disabilities. This suggests that there is a lack of strategic clarity regarding a public health role for learning disability nurses. This may lead to questions about the learning disability nurse's contribution to public health policy implementation and about how people with learning disabilities' access public health services.

In recent years NHS senior officials have outlined a public health role for learning disability nurses in England (DH 2007c) relating to developing and planning policy implementation and leading service delivery for people with learning disabilities. Recent government policy has focused on involving service users (DH 2002, 2003, 2005, 2006b 2007a, 2007d, Mencap 2004, National Patient Safety Agency 2004). It is therefore important to evaluate research on service users' perceptions of nursing care (Aylott 2002).

Literature search strategies

The review focused on two broad groups of studies. The first centred on the public health role of learning disability nurses and their involvement in public health policy implementation. The second looked at the experiences of people with learning disabilities in accessing public health services.

The work involved undertaking a computer database search using EBSCOhost, CINAHL, Academic Search Elite, Ovid Online, IBSS, Index to Theses, PsycARTICLES, ScienceDirect, RCN Journals Database,

ZETOC Search, Google Scholar and Copernic Plus. Search words were placed into two categories. One category contained the following key terms: learning disability; learning difficulty; mental retardation; intellectual disability. These were combined with words or phrases pertinent to the review: learning disability nurse, community learning disability nurse, role, public health, health promotion, public health policy, health care, views, perceptions.

Studies were excluded if they were published before January 1980, not in English, government documents or covered 'non-health' roles of nurses.

The search produced 75 relevant articles, which can be broken in four distinct groups:

- Studies that addressed a public health role of the learning disability nurse.
- Research that sought the perceptions and experiences of people with learning disabilities regarding access to public health/health care.
- Investigations that explored the implementation of health policy for people with learning disabilities.
- Articles that addressed the methodological challenges of carrying out perception and experience studies involving people with learning disabilities.

Literature was then read, summarised and themes identified.

Public health role

Bolland (2002) used case studies to provide a model of health promotion for people with learning disabilities. Marshall *et al* (2003) evaluated the impact of learning disability nurse-led health screening clinics and health promotion classes. Barr *et al* (1998) reported on a longitudinal health screening project led by learning disability nurses. The other five papers (Bolland 1997, Stewart and Todd 2001, Boarder 2002, Mobbs *et al* 2002, Hames and Carlson 2006) focused on questions around the awareness of other health professionals in primary care regarding the general contribution of the learning disability nurses.

Jukes (1994) traced the origins of learning disability nurses' involvement in public health to the 1960s. In the 1980s several attempts were made to identify and clarify the contribution of community learning disability nurses (Elliot-Cannon 1981, Royal College of Nursing 1985). The Griffiths report (1988) and the NHS and Community Care

Act (1990) emphasised the 'health' contribution of learning disability nursing. More recently, the DH has emphasised the public health role of learning disability nurses in England (DH 2001, DH 2007c).

There is, however, lack of clarity as to how this role is to be carried out in practice. This is because learning disability nurses find themselves treading a fine line between health and social care services. Consequently, defining a public health role for learning disability nurses has been difficult (Mobbs *et al* 2002). It is no surprise that the role has evolved differently across England (Mobbs *et al* 2002), or that primary care and social care providers have conflicting views on nurses' public health role (McGarry and Arthur 2001). There is very little research into learning disability nurses' practice and their contribution to public health services for people with learning disabilities (Boarder 2002). Recent research has concentrated on nurses' broader professional role (Mansell and Harris 1998, Alaszewski 2001, Mobbs *et al* 2002, Llewellyn and Northway 2007).

Predominantly qualitative methodologies were used in the research papers under review. These included a case study approach (Bolland 2002), questionnaires (Bolland 1997, Barr *et al* 1998, Mobbs *et al* 2002, Marshall *et al* 2003, Hames and Carlson 2006), a project report (Barr *et al* 1998) and semi-structured interviews (Stewart and Todd 2001, Boarder 2002). An outline of data analysis approaches was given in four studies under review. There was a content analysis (Boarder 2002), a descriptive analysis (Hames and Carlson 2006), and statistical analyses (Bolland 1997, Mobbs *et al* 2002). In all of the articles, except Bolland (1997), the authors do not pay much attention to the need for justifying their choice of research methods. Analysis and evaluation of this will be addressed in the section on methodologies.

Despite the methodological limitations highlighted here, important themes pertinent to the public health role of learning disability nurses emerge. The articles demonstrate high levels of health need among people with learning disabilities and the importance of action to improve access to public health services. Some of the emerging themes include the complexity and increasingly specialised role of the learning disability nurse (Mobbs *et al* 2002), the learning disability nurse's contribution to public health through health facilitation, health promotion and health education (Barr *et al* 1998, Bolland 2002, Marshall *et al* 2003), and the positive regard for learning disability nurses by other primary care professionals (Stewart and Todd 2001).

However, some of the emerging themes raise

Learning disability nurses find themselves treading a fine line between health and social care services

significant questions, which necessitate a need for further research. The lack of in-depth research studies that evaluate and validate the public health role of learning disability nurses must be addressed. Of even greater concern, perhaps, is the lack of public health role clarity among learning disability nurses themselves, other public health professionals and primary care organisations generally (Stewart and Todd 2001, Boarder 2002, Mobbs *et al* 2002, Hames and Carlson 2006). Studies have shown that a lack of role clarity impedes the implementation of health policy (Ross 2001, Fyson 2002). Taylor (1996) pointed out that lack of role clarity and confused and ambiguous expectations among healthcare professionals result in reduced quality of care. Clarity of role expectations is beneficial because it improves communication, flexibility and responsiveness at every level of policy implementation (Taylor 1996).

Health experiences

There is a growing amount of research literature on the involvement of people with learning disabilities in research (Townson *et al* 2004, Walmsley 2004). However, there appear to be very few studies that have examined the experiences of people with learning disabilities in accessing health care. Cameron and Murphy (2002) point out that a recent focus has been on how to meaningfully involve people with communication difficulties in research. This will be addressed in more detail in the section on methodologies.

Of the four studies under review in this section, the study by Martin *et al* (1997) was the most in-depth. The study sought to identify the expectations and experiences of people with learning disabilities and their carers about the health care they were receiving. The paper by Manthorpe *et al* (2003) reported on the views of people with learning disabilities and their carers on the changing roles and pre-registration education of learning disability nurses. The study by Young and Chesson (2006) investigated methods enabling people with learning disabilities and severe mental illness to comment on their health care. Chou *et al* (2008) examined whether women with a learning disability in an institution in Taiwan could comment on their experience of menstruation.

Martin *et al* (1997) used multiple methods to collect data. The other studies used focus groups (Manthorpe *et al* 2003), semi-structured interviews (Chou *et al* 2008) and structured interviews (Young and Chesson 2006). Only two studies explained how data was analysed; Manthorpe *et al* (2003) used thematic analysis and Chou *et al* (2008) used

comparative analysis. Only Manthorpe *et al* (2003) highlighted the advantages and limitations of their methodologies.

Informants have been used in research into the experiences of people with cognitive disabilities (McLoughlin 1996, Gilbert 2004). Manthorpe *et al* (2003) and Martin *et al* (1997) used carers as informants in their triangulated studies. Data from service users and carers was collected and analysed separately. Chou *et al* (2008) used in-depth interview questions answered by participants 'with assistance' from carers. There may be significant methodological questions about the outcomes of this research, given that there is evidence suggesting that people with learning disabilities can easily be influenced by others when responding to questions (Fraser and Fraser 2001).

A number of themes emerge. First, people with learning disabilities can be aware of their health needs. Second, people with learning disabilities can comment on their experience of health and health care. Third, people with learning disabilities can express their views on the contribution professionals make to their health care. Townsley (1995) noted that people with learning disabilities are increasingly being involved in evaluating services. *Valuing People* (DH 2001) saw a significant contribution from people with learning disabilities. Walmsley (2004) suggested that obtaining the views of service users is now a 'moral' requirement. However, what is missing from the studies under review are narratives from people with learning disabilities about the learning disability nurse's contribution to their experience of accessing public health services. How people perceive their experience of healthcare activity is likely to affect their future engagement with that activity (Zastowny *et al* 1995). It is therefore important to investigate how that experience is affected by learning disability nurses' involvement.

Health policy implementation

McDonnell *et al* (2006) pointed out that UK health policy is usually implemented or changed without evaluation. In addition, evaluation of health policy implementation has been neglected (Hill 2003, O'Toole 2004), leading to difficulties in determining whether such policy has been effective. Greenhalgh *et al* (2004) identified the need for action, as articulated by opinion leaders in health care.

The only study under review is that by Fyson (2002). This research investigated why health and social care policies for people with learning disabilities are difficult to implement and why there is such a disparity between policy and practice. The extensive study involved semi-structured interviews

with staff at all levels in learning disability services. Of interest among the findings is the worrying variation across geographical regions in the interpretation of national policy frameworks.

Northway *et al* (2007) pointed out that translating policy frameworks into operational policies is complex. In addition, policy effectiveness is dependent on implementation (Barrett 2004) and staff involved (Lipsky 1993, Northway *et al* 2007). Policy effectiveness is likely to affect service user experience. Therefore, research on how policy is implemented and its impact on service users is of importance and significance (Fyson 2002).

Research methodologies

Lack of justification for choice of methodologies is evident in most of the articles in this review.

This is surprising given that interpretive research methodologies have long been criticised for lack of rigour (Stringer 2007). The value and status placed on outcomes of research is largely dependent on the quality and rigour of methods used (Mays and Pope 2000).

There is increasing involvement of people with learning disabilities in service evaluation (Lowe 1992) and in research (Gates and Waight 2007) through focus groups. Focus groups are widely used in health research (Oliva *et al* 1999) and increasingly in qualitative research involving people with learning disabilities (McCallion and McCarron 2004, Gates and Waight 2007). McCallion and McCarron (2004) noted that focus groups are one of the most inclusive and relevant research approaches in learning disabilities. Another noted advantage of focus groups is their use in

References

- Alaszewski A, Gates B, Ayer S *et al* (2001) *Research Highlights: Educational Preparation for Learning Disability Nursing: Outcomes Evaluation of the Contribution of Learning Disability Nursing within the Multi-professional, Multi-agency Team*. English National Board, London.
- Aylott J (2002) Developments in learning disabilities nursing over the last 10 years. *British Journal of Nursing*. 11, 7, 498-500.
- Barr O, Gilgunn J, Kane T *et al* (1998) Health screening for people with learning disabilities by a community learning disabilities nursing service in Northern Ireland. *Journal of Advanced Nursing*. 29, 6, 1482-1491.
- Barrett SM (2004) Implementation studies: time for a revival? Personal reflections on 20 years of implementation studies. *Public Administration*. 82, 2, 249-262.
- Basch CE (1987) Focus group interview: an underutilized research technique for improving theory and practice in health education. *Health Education Quarterly*. 14, 4, 411-448.
- Beange H, McElduff, Baker W (1995) Medical disorders of adults with mental retardation - a population study. *American Journal of Mental Retardation*. 99, 6, 595-604.
- Beange H, Bauman A (1990) Caring for the developmentally disabled in the community. *Australian Family Physician*. 19, 10, 1558-1563.
- Boarder JH (2002) The perceptions of experienced community learning disability nurses of their roles and ways of working. *Journal of Learning Disabilities*. 35, 6, 281-296.
- Boland M, Daly L, Staines A (2008) Methodological issues in inclusive intellectual disability research: a health promotion needs assessment of people attending Irish disability services. *Journal of Applied Research in Intellectual Disabilities*. 21, 199-209.
- Bolland M (1997) Promoting the health care needs of people with learning disabilities. *British Journal of Community Health Nursing*. 2, 1, 46-51.
- Bolland M (2002) Health promotion and learning disabilities. *Health Education*. 16, 27, 47-55.
- Brown M (2007) Conducting focus groups with people with learning disabilities: theoretical and practical issues. *Journal of Research in Nursing*. 12, 2, 127-128.
- Cancer Research UK (2008) *Policy Statement - Inequalities in Cancer Experienced by Those with Learning Disabilities*. Cancer Research UK, London.
- Cameron L, Murphy J (2002) Enabling young people with a learning disability to make choices at a time of transition. *British Journal of Learning Disabilities*. 30, 105-112.
- Carey MA (1995) Comment: concerns in the analysis of focus group data. *Qualitative Health Research*. 5, 4, 487-495.
- Chou Y, Lu J, Wang F *et al* (2008) Meanings and experiences of menstruation: perceptions of institutionalized women with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. 21, ISSUE NO? 575-584.
- Department of Health (1999a) *Saving Lives: Our Healthier Nation*. DH, London.
- Department of Health (1999b) *Facing the Facts - Services for People with Learning Disabilities - A Policy Impact Study of Social Care and Health Services*. DH, London.
- Department of Health (2001) *Valuing People - A New Strategy for the 21st Century*. TSO, London.
- Department of Health (2002) *Shifting the Balance of Power: The Next Steps*. DH, London.
- Department of Health (2003) *Strengthening Accountability: Involving Patients and the Public*. DH, London.
- Department of Health (2005) 'Now I Feel Tall' - What a Patient-led NHS Feels Like. DH, London.
- Department of Health (2006a) *Our Health, Our Care, Our Say: A New Direction for Community Services*. DH, London.
- Department of Health (2006b) *A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services*. DH, London.
- Department of Health (2007a) *Getting Ready for LINKS: Planning your Local Involvement Workshop*. DH, London.
- Department of Health (2007b) *Valuing People Now*. DH, London.
- Department of Health (2007c) *Good Practice Guide in Learning Disabilities Nursing*. DH, London.
- Department of Health (2007d) *Our NHS, Our Future: NHS Next Stage Review*. DH, London.
- Disability Rights Commission (2006) *Equal Treatment: Closing the Gap*. DRC, Stratford Upon Avon.
- Elliot-Cannon C (1981) Do the mentally handicapped need specialist community nursing? *Nursing Times*. 77, 27, 77-80.
- Fraser M, Fraser A (2001) Are people with learning disabilities able to contribute to focus groups on public health? *Journal of Advanced Nursing*. 33, 2, 225-233.
- Fyson RE (2002) Defining the Boundaries: The Implementation of Health and Social Care Policies for Adults with Learning Disabilities. Unpublished PhD thesis. University of Nottingham.
- Gates B, Waight M (2007) Reflections on conducting focus groups with people with learning disabilities: theoretical and practical issues. *Journal of Research in Nursing*. 12, 2, 111-126.
- Gilbert T (2004) Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community*. 12, 4, 298-308.
- Greenhalgh T, Robert G, Macfarlane F *et al* (2004) Diffusions of innovations in service organizations: systematic review and recommendations. *Milbank Quarterly*. 82, 4, 581-629.
- Griffiths R (1988) *Community Care: Agenda for Action. Report for the Secretary of State for Social Services*. HMSO, London.
- Hames A, Carlson T (2006) Are primary care staff aware of the role of community teams in relation to health promotion and health facilitation? *British Journal of Learning Disabilities*. 34, 6-10.
- Hill M (2003) *Understanding Social Policy*. Seventh edition. Blackwell, Oxford.
- Hollins S, Attard MT, von Fraunhofer N *et al* (1998) Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*. 40, 1, 50-56.
- Howells G (1986) Are the medical needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners*. 36, 291, 449-453.
- Jacobson JW, Janicki MP, Ackerman LJ (1989) Health care service usage by older persons with developmental disabilities living in community settings. *Adult Residential Care Journal*. 3, 181-191.
- Jones RG, Kerr MP (1997) A randomized control trial of an opportunistic health screening tool in primary care for people with learning disabilities. *Journal of Learning Disabilities Research*. 41, 409-415.
- Jukes M (1994) Development of the community nurse in learning disability. *British Journal of Nursing*. 3, 15, 779-783.
- Kerr M (2004) Improving the general health of people with learning disabilities. *Advances in Psychiatric Treatment*. 10, ISSUE NO? 200-206.

addressing complex issues (Basch 1987).

However, inclusive research for people with learning disabilities using focus groups has significant challenges and criticisms (Owen 2001, Brown 2007, Gates and Waight 2007). Straw and Smith (1995) observed that focus groups with vulnerable people can easily become therapy sessions. Carey (1995) and Morgan (1995) pointed out that there are concerns regarding data analysis using this methodology.

Case studies (Fraser and Fraser 2001, Gates and Waight 2007) were used to evaluate focus groups in research involving people with learning disabilities. Boland *et al* (2008) emphasised the need for triangulation when using focus groups. All the studies acknowledged the challenges researchers face when using focus groups with people with learning disabilities, and Fraser and Fraser (2001)

and Gates and Waight (2007) offer advice on how these challenges can be addressed in practice. What is missing from the three studies is an evaluation of how data is processed and analysed. However, it is clear that focus groups involving people with learning disabilities are useful in exploratory, evaluative and longitudinal health research. Internal and external validity of data can be enhanced by triangulation.

Conclusion

This literature review has demonstrated a need to evaluate nurses' contribution to public health policy implementation. There is also a need to evaluate and validate the experiences of people with learning disabilities' in accessing public health; the review has highlighted a dearth of research evidence in this area (Langan *et al* 1994, Lennox *et al* 2000).

For author guidelines visit the *Learning Disability Practice* home page at www.learningdisabilitypractice.co.uk. For related articles visit our online archive and search using the keywords.

This article has been subject to double-blind review

Kay Mafuba is a senior lecturer in learning disabilities at the Thames Valley University, Middlesex

Kerr, M, Fraser W, Felce D (1996) Primary health care for people with learning disabilities - a group practice study. *Journal of Applied Research in Learning Disabilities*. 9, 347-352.

Langan J, Whitfield M, Russell O (1994). Paid and unpaid carers: their role in and satisfaction with primary health care for people with learning disabilities. *Health and Social Care in the Community*. 2, 6, 357-365.

Lennox N, Diggins J, Ugoni A (2000) The health needs of people with intellectual disability. *Medical Journal of Australia*. 173, 328-330.

Lipsky M (1993) Street-level bureaucracy: an introduction. In Hill M (Ed) *The Policy Process: A Reader*. Harvester Wheatsheaf, Hemel Hempstead.

Llewellyn P, Northway R (2007) The views and experiences of learning disability nurses concerning their advocacy education. *Nurse Education Today*. 27, 8, 955-963.

Lowe K (1992) Consumer based service: what consumers think. *The British Journal of Mental Subnormality*. 38, ISSUE NO? 6-14.

Mansell I, Harris P (1998) Role of the registered nurse learning disability within community support teams for people with learning disabilities. *Journal of Learning Disabilities for Nursing, Health and Social Care*. 2, 4, 190-194.

Manthorpe J, Alaszewski A, Motherby E *et al* (2003) Learning disabilities nursing - user and carer perceptions. *Journal of Learning Disabilities*. 7, 2, 119-135.

Marshall D, McConkey R, Moore G *et al* (2003) Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *Journal of Advanced Nursing*. 41, 2, 147-153.

Martin DM, Roy A, Wells M *et al* (1997) Health gain through screening - users and carers' perspectives of health care: developing primary health care services for

people with learning disabilities (1). *Journal of Intellectual and Development Disability*. 22, 4, 241-249.

Mays N, Pope C (2000) Qualitative research in health care: assessing quality in qualitative research. *British Medical Journal*. 320, 50-52.

McAllion P, McCarron M (2004) Using focus groups to elicit views across disciplines and national experiences with learning disabilities. *Journal of Policy and Practice in Learning Disabilities*. 1, 2, 88-94.

McDonnell A, Wilson R, Goodacre S (2006) Health policy: evaluating and implementing new services. *British Medical Journal*. 332, 109-112.

McGarry J, Arthur A (2001) Informal caring in late life: a qualitative study of the experiences of older carers. *Journal of Advanced Nursing*. 33, 2, 182-189.

McLoughlin DM, Cooney C, Holmes C *et al* (1996) Carer informants for dementia sufferers: carer awareness of cognitive impairment in an elderly community-resident sample. *Age and Ageing*. 25, 5, 367-371.

Mencap (2004) *Treat Me Right! Better Health for People with Learning Disabilities*. Mencap, London.

Mencap (2007) *Death by Indifference. Following Up the Treat Me Right Report*. Mencap, London.

Morgan DL (1988 YEAR?) *Focus Groups as Qualitative Research*. Sage, London.

Mobbs C, Hedley S, Wittering R *et al* (2002) An exploration of the role of the community nurse, learning disabilities, in England. *British Journal of Learning Disabilities*. 30, 13-18.

NHS Executive (1998) *Sign Posts for Success: in Commissioning and Providing Health Services for People with Learning Disabilities*. DH, London.

National Patient Safety Agency (2004) *Understanding the Patient Safety Issues for People with Learning Disabilities*. NPSA, London.

Northway R, Davies R, Mansell I *et al* (2007) Policies don't protect people, it's how they are implemented: policy and practice in protecting people with learning disabilities from abuse. *Social Policy and Administration*. 41, 1, 86-104.

O'Toole LJ (2004) The theory-practice issue in policy implementation research. *Public Administration*. 82, 2, 309-329.

Oliva G, Rienks J, McDermid M (1999) What high-risk women are telling us about access to primary and reproductive health and HIV prevention sources. *Aids Education and Prevention*. 11, 513-524.

Owen S (2001) The practical and methodological and ethical dilemmas of conducting focus groups with vulnerable clients. *Journal of Advanced Nursing*. 36, 5, 652-658.

Ross J (2001) Role Identification - An Impediment to Effective Core Primary Health Care Teamwork. Victoria University of Wellington. <http://researcharchive.vuw.ac.nz/handle/10063/85> (Last accessed: March 12 2009.)

Royal College of Nursing (1985) *The Role and Function of the Domiciliary Nurse in Mental Handicap*. RCN, London.

Stein K, Allen N (1999) Cross sectional survey of cervical cancer screening in women with learning disabilities. *British Medical Journal*. 318, 641.

Stewart D, Todd M (2001) Role and contribution of nurses for learning disabilities: a local study in a county of Oxford-Anglia region. *British Journal of Learning Disabilities*. 29, 145-150.

Straw RB, Smith MW (1995) Potential uses of focus groups in federal policy and program evaluation studies. *Qualitative Health*

Research. 5, 4, 421-427.

Stringer ET (2007) *Action Research: A Handbook for Practitioners*. Third edition. Sage, Newbury Park, California.

Taylor JC (1996) Systems thinking, boundaries, and role clarity. *Clinical Performance and Quality Health Care*. 4, 4, 198-199.

Townsley R (1995) Avon calling. *Community Care*. 2, 18, 26-27.

Townson L, Macauley S, Harkness E *et al* (2004) We are all in the same boat: doing 'people-led' research. *British Journal of Learning Disabilities*. 32, 72-76.

Walmsley J (2004) Inclusive learning disability research: the (nondisabled) researcher's role. *British Journal of Learning Disability*. 32, 72-76.

Wanless D (2004) *Securing Good Health for the Whole Population: Final Report*. HM Treasury, London.

Wilson DN, Haire A (1990) Health care screening for people with mental handicap living in the community. *British Medical Journal*. 301, 1379-1381.

Young AF, Chesson RA (2006) Obtaining views on health care from people with learning disabilities and severe mental health problems. *British Journal of Learning Disabilities*. 34, 11-19.

Zastowny TR, Stratman WC, Adams EH *et al* (1995) Patient satisfaction and experience with health services and quality of care. *Quality Management Health Care*. 3, 3, 50-61.