

Equal Treatment: Closing the Gap

Final Report from the Welsh Centre for Learning Disabilities to the Disability Rights
Commission

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October 2005

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Introduction

This report is arranged in a number of sections:

Section 1: Literature Review

Our ongoing work on health disparity means that we have attempted to keep generally abreast of published literature on the topic. We have therefore included a descriptive review of the literature as a helpful adjunct to the reporting of our secondary analyses of the PEARL databases. The review is structured under three headings: (a) Health concerns, (b) Access to primary care, and (c) Health care policy and health checks for people with learning disabilities. However, we stress that this does not constitute a systematic review of the literature.

Section 2: Summary of the PEARL Databases

A brief overview is given of the PEARL databases and of the sampling and measurement procedures which produced them.

Section 3: A Summary of morbidity found in the PEARL sample

In this section, rates of occurrence of various impairments, conditions or health indicators found among the PEARL sample are described.

Section 4: Level of unmet need

The extent of previously unidentified morbidity identified at first health check within the PEARL sample is described. Treatment undertaken following health checking is also described.

Section 5: Level of new unmet need at a subsequent health check

The extent of new morbidity identified at a follow-up health check is described and analysed according to time interval between health checks.

Section 6: Access to health promotion

The frequency of uptake of health promotion actions in a population of adults with a learning disability identified in primary care is described.

Section 7: Frequency of contact with primary and secondary care

The frequency of contact with specialists, health promotion actions and GP consultations for eight 6-month periods before and seven after the first health check is described.

Section 8 : An investigation into the experiences of people with mild learning disabilities when visiting their doctor's surgery

The results are described of five focus groups conducted with adults with learning disabilities able to understand the purpose of the inquiry and articulate their views on their experiences of using primary care services.

Section 9: Reanalysis of the Mencap Cymru Database

The Mencap Cymru database was established as part of Mencap Cymru's contribution to the Treat Me Right campaign. This section summarises findings of questionnaires completed by or on behalf of 178 adults with learning disabilities.

Section 10: Primary care team views about the presence of health inequalities among people with learning disabilities and potential solutions to them

A questionnaire was sent to 24 general practices which participated in the PEARL research to elicit the extent to which primary care team members acknowledged the existence of various health inequalities among people with learning disabilities suggested by the literature, what they thought the reasons for this were and what they felt were the solutions to them, if any. The findings of 11 returned questionnaires and comments made during telephone follow-up from two practices are described.

Section 11: Local Health Board views about the presence of health inequalities among people with learning disabilities and potential solutions to them

A questionnaire was sent to the 22 Local Health Boards in Wales to gain information about local measures to address health inequalities. In addition, a final question addressed measures being taken to meet the requirements of the Disability Discrimination Act. The findings of 12 returned questionnaires are described.

Section 12: Conclusion

A brief synthesis of the results and conclusions from the preceding sections is presented.

Ethical permission was granted for the study: LREC reference number 05/WMW02/71.

Section 1: Literature Review

1.1 Health concerns

People with learning disabilities have repeatedly been found to have untreated morbidity which among other members of the community one would expect to have been identified and resolved (Howells, 1986; Wilson & Haire, 1990; Beange & Bauman, 1991; Webb & Rogers, 1999). They also receive lower levels of health promotion and preventative care, are more vulnerable to certain morbidities and experience higher rates of mortality than the general population (Beange et al., 1995; Hollins et al., 1998; Kerr et al., 1996; Leeder & Dominello, 2005; Maaskant et al. 2002; McGuigan et al. 1995; Sutherland et al. 2002; Whitfield et al., 1996).

People with learning disabilities experience the same range of health concerns as the general population. However, certain conditions are more common, serious or less well treated, such as epilepsy, sensory impairment, respiratory problems, dental problems, incontinence and being underweight or overweight (Beange et al., 1995; Chaney et al., 1979; Kappell et al., 1998; Kendall, 1992a; Springer, 1987; Sutherland et al. 2002; Turner & Moss, 1996; Wood, 1994). In addition, although longevity among adults with learning disabilities has increased in the last three decades, they still tend to have reduced life expectancies in comparison with the general population (Janicki & Breitenbach, 2000; Janicki et al., 1999; Patja et al., 2000; Strauss et al., 1999). Factors underlying increased mortality include aetiology such as Down's syndrome (e.g., Patja et al. 2000) and functional limitations arising from level of intellectual, neurological or physical impairment (e.g., Chaney & Eyman, 2000; Hayden, 1998; Janicki et al., 1999; Strauss et al., 1999). While it should be recognised that aetiology and functional impairments are confounded, the most common risk factors associated with increased mortality include lower IQ, non-ambulation, poor motor skills, inability to feed oneself, poor self-help skills and poor communication.

The White Paper *Saving Lives: Our Healthier Nation* (DoH, 1999) outlined four priority target areas for saving lives and improving health: cancer, coronary heart disease and stroke, accidents and mental illness. It emphasised the need to minimise risk factors for ill health associated with personal lifestyles: poor diet, obesity, lack of physical activity, alcohol misuse and smoking. The prevalence of heart disease and cancer have been reported as relatively low in people with learning disabilities (Adlin, 1993; Carter & Jancar, 1983; Cooke, 1997; Welsh Office, 1996). Despite this, several studies have shown that heart disease is a prevalent cause of death in those with mild to severe learning disabilities (Patja et al., 2001).

Rimmer et al. (1994) showed that 23% of the adults with learning disabilities in their sample were considered borderline high risk and 17% were at high risk of cardiovascular disease. As would be expected from the normal ageing process, cardiovascular disorders are found at higher rates in the elderly (Schrojenstein Lantman-de Valk et al., 1997; Cooper, 1998), by which age the prevalence of cardio and cerebrovascular disease is similar to that of the general population (Evenhuis, 1997). Occurrence of cancers similarly varies with age (Patja et al., 2001; Welsh Office, 1996). People with Down's syndrome are at particular risk from heart problems both from their vulnerability to heart defects from birth and from their susceptibility to premature ageing (Tubman et al., 1991; Nespoli et al., 1993).

Risk of heart disease and cancers, however, may alter as individuals, particularly those with mild learning disabilities, live longer, have less restricted lifestyles and exercise greater self-determination to adopt the habits of the general population, such as fatty diets, smoking and the use of alcohol (Holland, 2000; Kappell et al., 1998; Moss & Turner, 1995; Patja et al., 2000; Rimmer et al., 1993; Robertson et al., 2000). In terms of lifestyle health-related risk behaviour, people with learning disabilities smoke and use alcohol less than the general population (Adlin, 1993; Moss & Turner, 1995; Rimmer et al., 1995; Robertson et al., 2000). Moreover, a recent study (Taylor et al., 2004) found no evidence of the prevalence of smoking increasing. However, problems of poor diet, weight and physical inactivity are more prevalent.

Obesity has a range of associated health problems including heart disease, some forms of cancer, hypertension, diabetes and respiratory problems (Burkart et al., 1985; Bell & Bhate, 1992; Moss & Turner, 1995; Turner & Moss, 1996). People with learning disabilities may have more difficulties with maintaining a healthy weight due to additional morbidities such as physical impairments, the side effects of medication, dependence on others to monitor diet and reduced access to information on a healthy lifestyle (Jackson & Thorbecke, 1982; Springer, 1987; Simila & Niskanen, 1991; Bell & Bhate, 1992; Hove, 2004; Wood, 1994). The proportions of women with learning disabilities found to be obese in several studies (Beange et al., 1995; Bell & Bhate, 1992; Emerson, 2005; Rimmer et al. 1993; Robertson et al., 2000; Turner, 1997) are higher than that for women in the UK population generally (Office of National Statistics, 2001). The proportions of men with learning disabilities found to be obese are lower than the proportions for women and generally similar to that for all men in the UK population. Apart from gender, obesity has been associated with less severe intellectual impairment (Hove, 2004; Rimmer et al., 1993; Robertson et al., 2000), living in a less

restrictive community setting or family home (Rimmer et al. 1993; Rubin et al., 1998) and Down's syndrome (Hove, 2004; Robertson et al., 2000).

Less attention has been paid to the health risk of being significantly underweight than to obesity. Being underweight is associated with increased susceptibility to infection and reduced capacity for physical or mental activity or work. Available evidence suggests that significantly higher proportions of men and women with learning disabilities in residential services are underweight than their counterparts in the general population (Kennedy et al., 1997; Robertson et al., 2000), with the degree of malnutrition being related to the severity of feeding difficulties people experience. As research has indicated that the polarisation of weight problems, both being over and underweight, is more marked outside of residential services (Wood, 1994), eating a balanced diet is a particularly important general concern.

Turner (1997) and Robertson et al. (2000) reported that only a minority of service users with learning disabilities ate the recommended proportions of starch, fruit and vegetables, protein and dairy products considered to constitute a healthy, balanced diet. Similar minorities were considered to have poor or fatty diets. Evidence has suggested, however, that lack of knowledge about nutrition may not be the issue, as obese individuals within the learning disabled population have been found to possess greater knowledge about healthy eating and nutrition than their non-obese counterparts (Golden & Hatcher, 1997). Moreover, individuals may not control their diets themselves. Those reliant on services or care from their families may depend on others to monitor healthy intake.

Physical inactivity is a risk factor for cardiovascular disease, some cancers and type 2 diabetes. Physical exercise may increase self-esteem (Castagno, 2001), reduce depression (Heller, et al., 2004; Lawler & Hopker, 2001), lessen challenging behaviour (Gabler-Halle et al., 1993; Lancioni & O'Reilly, 1998) and impede cognitive decline in middle and old age (Richards et al., 2003). In general, the available evidence demonstrates that adults with learning disabilities are much more likely to lead extremely sedentary lifestyles than the population at large. For example, Beange et al. (1995) reported that 72% of men and 75% of women with learning disabilities had not engaged in moderate to vigorous physical activity in the preceding two weeks compared with 49% of men and 65% of women in the general population. In the UK, physical inactivity has been defined as participating in moderate or vigorous physical activity less than 12 times in four weeks, a level of inactivity which represents a risk factor for cardiovascular disease (Bennett et al., 1995) By this standard, rates of inactivity found among various groups of adults with learning disabilities cluster

around 90% (Emerson, 2005; Messent et al., 1998; Turner, 1997), a level comparable to that found in the 75+ age group in the general population. These data are reinforced by the consistency of findings in more general studies of the engagement in activity of people in staffed community housing showing that constructive occupation varies inversely with level of learning disability and that people with more severe or profound learning disabilities are not effectively supported to take advantage of everyday opportunities for activity (Felce & Emerson, 2004). A general picture of inactivity has been reported in other countries (Ouellete-Kuntz, 2005)

Accidental injury is a major preventable public health problem for the general population (Grossman, 2000). A number of risk and protective factors influence injury rates (Rivara, 1994; 1995). In particular, the presence of intellectual impairment is a substantial risk for unintentional injury (Dunne et al., 1993; Sherrard et al., 2001), the latter reporting that a representative sample of children and adults aged 5-29 years were found to have substantial excess injury mortality and double the injury morbidity than their counterparts in the general population. Psychopathology, epilepsy and an overly sociable temperament have been identified as independent risk factors for injury to people with learning disabilities (Diekema et al., 1993; Sherrard et al., 2001). Other factors potentially influencing injury risk include sensorimotor deficits, impaired causal reasoning and a reduced capacity to cope with environmental challenges (Dunne et al., 1993; Rivara, 1995).

People with learning disabilities are generally thought to be more likely to experience mental health problems than the general population (Deb et al., 2001; Cooper, 1997; Moss, 1999; Moss et al., 1998). However, diagnosis of psychiatric illness in people with learning disabilities is complicated by a number of factors including the possibility of atypical expression and the difficulty of applying classifications dependent on reported internal states to individuals who cannot communicate. Prevalence studies of psychiatric disorders in people with learning disabilities report markedly varying rates, (Deb et al., 2001; Hatton, 2002) depending on definitions of disorders, method of case identification, population studied and whether behaviour disorders or behaviourally defined syndromes such as autism are included. The distribution of psychiatric disorders is also different to that found in the general population with lower rates of substance abuse, affective disorders and neurotic disorders but higher rates of psychosis, dementia and autism. Higher levels of dementia, generalised anxiety disorder and depression are found in older populations (Cooper, 1997). Some common mental health problems in the general population, such as depression, may be

under-recognised among people with learning disabilities as symptoms of lethargy and withdrawal for example may be misconstrued as arising from intellectual impairment. The high rate of prescription of antipsychotic medication, particularly in comparison to the much lower rate of diagnosis of psychosis, has led to concern that people are being unnecessarily exposed to unpleasant and potentially harmful medication side-effects (Ahmed et al., 2000).

Higher rates of visual and auditory sensory impairment have been found in people with learning disabilities than in the general population (Beange & Bauman, 1991; Harris, 1978; Howells, 1986; Kappell et al., 1998; Tielsch et al., 1990; van Schrojenstein Lantman-de Valk et al., 1997; Warburg, 1994). People with severe or profound disability are more likely to be affected by visual impairments than non-disabled people and therefore need appropriate screening (Kwok et al., 1996; McCulloch et al., 1996; Woodhouse et al., 2000). Dual sensory impairment is also more common in people with more severe learning disabilities. Both sensory impairments are more common among people with Down's syndrome and both are affected by ageing (Evenhuis, 1995; van Schrojenstein Lantman-de Valk et al., 1997). Early detection and treatment for sensory impairment has been advocated both to ameliorate impairment and to increase individuals' acceptance and use of sensory aids. Assistive devices such as glasses and hearing aids have been used successfully by people with learning disabilities including the elderly (Evenhuis, 1995a; 1995b).

Studies of children and adults with learning disabilities have suggested that between one fifth and one third of individuals will have active epilepsy, that is to have continued seizures or continued anti-epileptic drug therapy, in comparison to 0.7-1% or less in the general population, with prevalence proportional to the degree of learning disability (Branford et al., 1998; Lewis et al., 2000; Mariani et al., 1993; Morgan et al., 2004; Richardson et al., 1981). Difficulties in the diagnosis of epilepsy have been highlighted, particularly for individuals with communication difficulties unable to express the subjective experience or with movement disorders or stereotyped behaviour which mimic some seizure types (Paul, 1997). Epilepsy is also more complex among people with learning disabilities due to the presentation of multiple seizure types and the high severity of epileptic seizures found in individuals, which are resistant to treatment (Branford et al., 1998; Tobias, 1994). The condition has been found to reduce life expectancy in individuals with all severities of learning disability (Morgan et al., 2001; Patja et al., 2000).

UK studies of people with learning disabilities have identified respiratory disease as the cause of death in approximately half of cases, compared to about 8% in the general population

(Carter & Jancar, 1983; Hollins et al., 1998). A more recent nation-wide survey in Finland, however, identified the percentage dying from respiratory disease as 22%, which was lower than the rate of deaths due to cardiovascular problems (Patja et al., 2000). Mortality from respiratory disease has been found to be considerably higher for individuals with severe learning disabilities than those with mild or moderate learning disabilities (Chaney et al., 1979; Patja et al., 2000). Those who are immobile, have additional impairments, have problems with food aspiration or who are underweight are more at risk (Chaney et al., 1979; Kennedy et al., 1997).

Studies have shown that people with learning disabilities have poor oral hygiene and a high prevalence of gum disease and calculus (Gizani et al., 1997; Kendall, 1992b; Shaw et al., 1989). Non-disabled individuals have been found to have better dental hygiene, less gum inflammation, more fillings and fewer extractions, but more untreated caries, than individuals with a learning disability (Kendall, 1992a). Adults living in family homes have been found to have significantly more untreated decay and poorer oral hygiene than those living in staffed homes (Tiller et al., 2001). Some forms of medication can cause periodontal problems. For example, the anti epileptic, phenytoin, has been associated with gingivitis (Majola et al., 2000). Research also indicates that the extent of restorative care can be highly variable and that people with learning disabilities are not an homogenous group in this respect (Cumella et al., 2000; Kendall, 1992b). Cumella et al. (2000) comment on the problems of self-report of dental problems and the lack of awareness among carers leading to under-identification. Reluctance to accept treatment and access and consent to care are other potentially problematic issues. Consistent with this, Minnes et al. (2003) found that 25% of all individuals with intellectual disabilities in a Canadian study sample had unmet dental needs.

Learning disability has many genetic causes, each of which may give rise to particular health needs (see O'Brien & Yule, 1995). People with Down's syndrome have a higher incidence of sensory impairments, heart problems, leukaemia, thyroid problems, skin disorders, musculoskeletal conditions, respiratory problems, premature ageing and Alzheimer's disease. People with Prader Willi syndrome are susceptible to scoliosis, visual problems, diabetes and certain heart defects and arrhythmias. People with Fragile X syndrome have a vulnerability to certain heart defects, central nervous system dysfunction, epilepsy, sensory impairments and dental abnormalities. People with Noonan syndrome also have a susceptibility to heart defects and sensory impairments. In addition, a range of conditions are associated with characteristic psychological and behavioural problems such as self-injury in Cornelia de

Lange and Lesch-Nyhan syndromes; obesity associated with insatiable hunger in Prader Willi syndrome, inappropriate laughter in Angelman syndrome, stereotypic hand movements in Rett syndrome and feeding difficulties and emotional and social problems in Williams syndrome. Moreover, in general, learning disability is associated with a variety of health-related behavioural deficits or excesses such as incontinence and sleep problems for which advice from the primary care team may be sought.

1.2 Access to primary care

Although people with learning disabilities are at higher risk of a range of health problems which result in them having higher health care needs than the general population, they do not access primary health care at a commensurate level (Beange & Bauman, 1991; Howells, 1986; Whitfield, Langan, & Russell, 1996; Wilson & Haire, 1990). This is consistent with the more general finding that people who may be regarded as medically 'vulnerable' tend to use primary care services less than those with a lesser predisposition for ill health (Broyles et al. 2000; Fouts et al., 2000). Community based primary health care teams used by the general population are a responsive rather than proactive service, relying heavily on the ability of the patient to contact and communicate with the general practitioner and other members of the team. This system of care is becoming the sole access route to secondary and specialist care for individuals with a learning disability, now that it is the main health care provider for this population (Kerr et al., 1996; Starfield, 1994). However, the adequacy of primary care with respect to people with learning disabilities is not just a matter of the frequency of contact befitting the level of health need. The additional and often complex difficulties associated with intellectual impairment mean that the nature of the consultation and the quality of practitioner-led identification of ill-health has also to be adjusted to this population.

Despite the need for enhanced attention to their health, people with learning disabilities access primary care no more than the general population (Wilson & Haire, 1990; Whitfield et al., 1996). They have a lower involvement in health promotion actions than the general population, particularly receiving less by way of routine immunisations and blood pressure checks, oral care, cervical and breast cancer screening programmes and measures related to avoiding cardiovascular disease (Beange & Durvasula, 2001, Lewis et al., 2002; Ouellete-Kuntz, 2005; Webb & Rogers, 1999). A number of factors have been identified which may lessen access, including poverty and limited choice of transport (Beange, 1996), dependence on others to facilitate attendance at the surgery (Minihan et al., 1993; Chambers et al., 1998), communication difficulties (Wilson & Haire, 1990; Beange et al., 1995), behavioural difficulties

which affect the consultation (Minihan & Dean, 1990), the lack of confidence and specialist knowledge of general practitioners in the area of learning disabilities (Lennox et al., 1997; Stanley, 1998) and the additional time and resources required by some patients (Eyre, 1996; Stein & Ball, 1999).

Studies have shown rates of mobility difficulties in among samples of people with learning disabilities of 10-18% (Kiernan & Moss, 1990; Lowe & Felce, 1995b; McGrother et al, 1996) increasing in populations of older individuals up to 32% (Cooper, 1998; Hand, 1994; Haveman et al, 1989). Where motor impairment occurs professionals may find it more difficult to perform physical examinations. Challenging behaviour has been found among about 17% of study samples in the UK (DHSS, 1972; Kushlick & Cox, 1973; Qureshi & Alborz, 1992), although the prevalence of behaviour which causes problems for patient examination or treatment cannot be directly inferred. Behaviour is situation specific and individuals who do not usually exhibit challenging behaviour may become extremely distressed during a consultation. Minihan & Dean (1990) found 20% of patients with learning disabilities could only be examined or treated after supportive measures such as pre-medication or pre-visits for desensitisation. In similar vein, patients with a psychiatric illness may also demonstrate challenging behaviour that could obstruct care.

Problems in interpreting a person's behaviour, due to unusual response patterns (Lennox et al., 1997) and distinguishing between fear of a medical procedure and a patient's legal right to refuse treatment (Minihan et al, 1993) have been highlighted as sources of difficulty for general practitioners. Only one in five primary care doctors reported that they felt well prepared to manage a situation in which a patient with learning disabilities refuses to co-operate with an examination or treatment (Minihan et al, 1993). Moreover, Howells (1986), reported that some parents were deterred from visiting the doctor due to embarrassment caused by the behaviour of their adult offspring.

Between 50% and 90% of people with learning disabilities have communication difficulties according to the definitions used and the sample surveyed (Van der Gaag, 1998). McLean et al. (1996) showed that 59% of a representative sample of people with severe learning disabilities had some skills in symbolic communication (43% in children and 80% in adults) while 19% had no verbal skills but did demonstrate intentional communication (24% in children and 14% in adults) and 21% had no intentional communication skills (33% in children and 6% in adults). People with learning disability are therefore often reliant on their family or carers to identify and communicate their health needs. This reliance has been found to be a

major barrier to care. In a study of adults with learning disabilities attending a day centre, Wilson & Haire (1990) discovered that health problems had been overlooked in instances when carers believed the person to be in good health. Similarly, Beange et al. (1995) found that 65% of patients and 24% of carers reported no symptoms, when independent examination revealed a mean of 5.4 medical problems per patient. Evenhuis (1997) found that elderly people with learning disabilities tended to tolerate symptoms or express them atypically as irritability, inactivity, loss of appetite or problems in sleeping.

Difficulties with history taking and communication have been highlighted where people with a learning disability cannot speak for themselves or are slow at getting information across (Lennox et al., 1997; Kerr, 1998;). People with learning disabilities may need longer or additional consultations to address certain medical problems (Chambers et al., 1998). Duckworth et al. (1993) investigated the skills involved in interviewing people with learning disabilities. They commented that time constraints may force the doctor to ignore the patient in order to elicit information more quickly from a carer. Problems can be exacerbated for patients in residential services if staff turnover results in carers without adequate knowledge accompanying the patient (Crocker et al., 1987; Lennox et al., 1997), a factor which may be difficult for the doctor to influence unless there is an existing relationship with the staff group. Accurate medical records, however, can reduce many of the difficulties for the doctor caused by unreliable information (Crocker et al., 1987).

In the UK, general practitioners have been reported as feeling a lack of confidence in treating people with learning disabilities (Lennox et al., 1997; Stanley, 1998). In a recent study (Stein, 2000), no GP reported feeling totally confident in treating individuals with a learning disability, although, 45% said they did some of the time and 49% reported feeling confident most of the time. Lack of confidence is less common among GPs who have had some specialist training (Stanley, 1998). In this regard, GPs have highlighted the usefulness of practical resources such as handbooks, resource guides, lists of specialist physicians, and policy documents on informed consent (Minihan et al., 1993; Lennox et al., 1997). Two thirds of doctors surveyed in the UK were unaware of the correct procedures for consent to treatment for people with learning disabilities, according to English law (Turner et al., 1999).

Research has also highlighted the need for specialist care for this population and emphasised the need for contact and good referral paths to other health professionals and services with expertise in learning disabilities (Minihan & Dean, 1990; Strauss & Kastner, 1996). However, the primary care team have been found to lack knowledge of available specialist services and

be reluctant to contact them (Bernard & Bates, 1994; Minihan et al., 1993; Stanley, 1998; Stein, 2000), despite apparently positive attitudes about the value of specialist learning disability teams (Kerr et al., 1996).

The additional health needs inherent in people with learning disabilities imply a higher level of resource input, if they are to be adequately addressed. Studies have found that patients with intellectual disabilities have higher consultation rates, out of hours visits and contact with specialist services (Eyre, 1996; Stein & Ball, 1999; Morgan et al., 2000). This increased use of services is believed to be even higher for those resettled from long stay institutions where, in some instances, the workload involved was found to be four to five times greater than for the non learning disabled (Chambers et al., 1998; Martin & Martin, 2000). People with learning disabilities have also been found to have a higher number of hospital admissions and a greater average length of stay in hospital than the general population (Walsh et al., 1997). However, care co-ordination (e.g. organising referrals, maintaining and communicating medical record information and assisting and supporting patients to access health care services appropriately) has been found to reduce length of stay in hospital, readmission rates and hospital charges (Criscione et al., 1993). McConkey & McAteer (1999) have also argued that care co-ordination is essential to ensure services are delivered in a cost effective manner given the number and range of different professionals typically involved.

1.3 Health care policy and health checks for people with learning disabilities

Recent UK learning disability policy has highlighted a need for general practice to address the possible deficiency in caring for such a vulnerable population (Learning Disability Advisory Group, 2001; Department of Health, 2001). Such policy has suggested that pro-active health checking may be a means by which the under-identification of treatable morbidity might be addressed. Research has provided some evidence of the utility of health checks in this regard, although their impact in terms of promoting health and quality of life has not, as yet, been fully explored (Martin et al., 1997; Webb & Rogers, 1999).

From the late 1990s onwards, the NHS Executive (1998; 1999) began to give good practice guidance to commissioners and providers of health care and to primary care teams about how to address the problem of unmet need for people with learning disabilities, while a contemporaneous report (Department of Health, 1999) highlighted the inconsistencies in health service provision across the country, particularly in relation to individuals with severe or multiple impairments, and the lack of clarity in NHS responsibilities. Since then, policy in Great Britain has recommended special arrangements with respect to people with learning

disabilities in order that their health needs are adequately addressed. In England, the White Paper, *Valuing People*, (Department of Health, 2001) set out specific deadlines for all people with a learning disability to be registered with a general practitioner, have a 'health facilitator' and a 'health action plan' In Scotland, *A Partnership for a Better Scotland* (Scottish Executive, 2003) advocated piloting of health screening for people with learning disabilities and a subsequent Health Needs Assessment Report, *People with Learning Disabilities in Scotland* (NHS Health Scotland, 2004) recommended the introduction of written anti-discrimination policies at a local level supported by widespread induction training on the needs of people with learning disabilities for relevant staff, the provision of required supports to enable equality of access, the development of accessible health promotion responsive to the particular priorities of people with learning disabilities, the implementation of health screening and inclusion of health improvement considerations within the 'Single Shared Assessment' developed for each individual. In Wales, advice to the Welsh Assembly Government in the report *Fulfilling the Promises* (Learning Disability Advisory Group, 2001) recommended the provision of accessible information on healthy living to people with learning disabilities, the development of a learning disability database by each general practice so as to target interventions and health promotion appropriately, the implementation of regular health checks and a system for following up outcome. Subsequent Section 7 guidance issued by the Welsh Assembly Government repeated the need for accessible information and suggested that Local Health Boards might consider enhanced arrangements including the implementation of practice-based registers and regular audited formalised health checks. It also recommended that the multi-disciplinary Unified Assessment process co-ordinated by local authorities should identify and plan for health needs as well as social care needs.

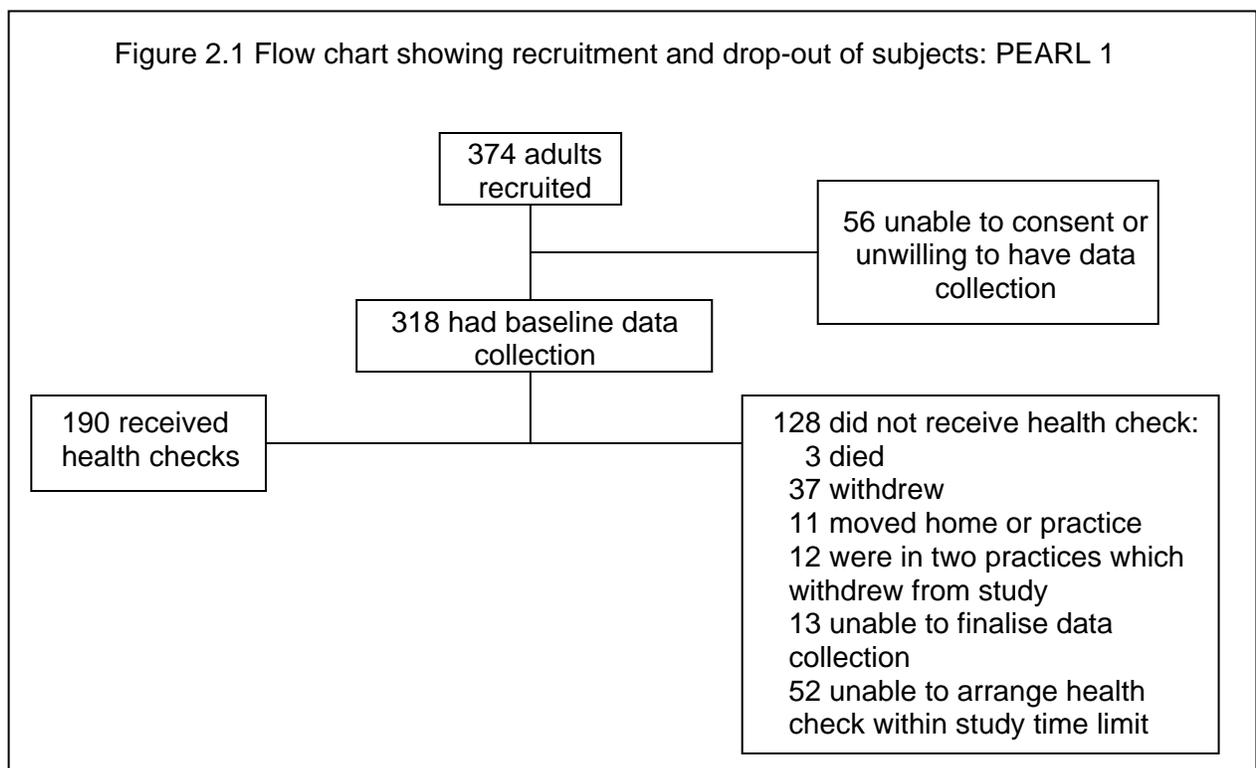
In the absence of an individual being able to request a doctor's care, there is a clear logic to health care being proactive rather than responsive. The need for individuals with learning disabilities to have a regular medical examination and general assessment has been articulated by the Royal College of General Practitioners (1990). Although patients with disability may fail to report symptoms, conditions can be diagnosed as accurately as for patients in the general population, as long as health professionals use routine diagnostic screenings with a knowledge of risk factors and atypical presentations, in addition to taking account of carer observations (Evenhuis, 1997). Annual health checks have been found to be effective in identifying health needs in Australia (Beange et al., 1995), New Zealand (Webb & Rogers, 1999) and the UK (Martin et al., 1997, Baxter et al., in press).

There has been some debate over which group of health professionals should be primarily responsible for conducting health checks: the primary care team, the community learning disability team or indeed carers (Matthews & Hegarty, 1997; Barr et al., 1999; Curtice & Long, 2002). The primary care team has an advantage as the focus for health checking since policy has consistently stressed the importance of including people with learning disabilities within generic arrangements and, in any case, the GP is the route via which to access other specialist services. However, despite these rationales, studies have reported a reluctance on the part of general practitioners to perform annual health checks without additional remuneration (Lennox et al., 1997; Stein, 2000; Gill et al., 2002). Moreover, while there are obvious benefits for the health checks to be conducted by the individual's general practitioner; studies have indicated the value of involving nurses in their implementation (Barr et al., 1999; Hunt et al., 2001). In the use of health checks for the elderly, nurses placed a higher value on the use of health assessments and found a higher level of unmet need than general practitioners (Chew et al., 1994; Tremellen, 1992).

Section 2: Summary of the PEARL Databases

Forty general practices within three health authorities in South and Mid Wales participated in the PEARL research. They had a combined registered patient population of 354,000, 20% of the 1.8m in the territory. Each practice identified their adult patients with an intellectual disability with help from the research team and nominated them for the study after they had gained permission to do so. They then recruited them into the study using a pro forma letter. This process resulted in a potential sample of 374 adults. Based on information from 16 practices on the total number of individuals identified as opposed to those referred to the research team, it was estimated that the 40 practices would have identified a total of about 745 adults. This is somewhat lower than the 995 which would be predicted from the total number of adults on learning disability registers in Wales for that year extrapolated to a similar base population.

After written consent had been obtained, or assent from carers when the patient lacked the capacity to consent, an initial sample of 318 adults was achieved. Baseline data included age, gender and assessments of behavioural characteristics, challenging behaviour, social impairment and the triad of social impairments characteristic of autism. In PEARL 1, health checks were conducted for 190 adults (60%); 128 of the initial 318 people moved, died or withdrew from the study, or refused or did not receive a health check (see Figure 2.1).



The characteristics of the initial PEARL 1 (n=318) and final PEARL 1 (n=190) samples are given in Table 2.1. There are areas where the initial sample was not representative of the population of people with intellectual disabilities as a whole. For example, one would have expected slightly more males than females and fewer to be living in staffed accommodation. However, in other aspects, including age, ability and presence of challenging behaviour, the sample characteristics were in line with other surveys. The final sample was similar to the initial in terms of age, gender, adaptive behaviour, challenging behaviour, social impairment, and threshold indicators of mental illness, although the final sample had a higher proportion from staffed accommodation.

Table 2.1. Characteristics of subjects in the initial and final PEARL 1 samples

	Mean age (range)	% Male	% Staffed home	Mean ABS ¹ score (range)	Triad of Social Impairments ² (%)	Challenging Behaviour (%)	Indication of Mental Illness ³ (%)
Initial PEARL 1 Sample (n=318)	41.46 (17-86)	43.7	45.6	171.21 (14-304)	33.0	14.8	45.9
Final PEARL 1 Sample (n=190)	42.76 (17-86)	43.2	53.7	166.90 (31-304)	33.7	16.3	43.6

¹ ABS=Adaptive Behavior Scale (Nihira et al. 1993) - a measure of presence/absence of independent skills

² The triad of social impairments is characteristic of autism spectrum disorder (Wing & Gould, 1979)

³ Meeting threshold levels on the Psychopathology Instrument for Mentally Retarded Adults (16)

In addition to the adult sample, a sample of 79 children was also recruited. Similar limited baseline data were collected (see Table 2.2). However, information of health status was restricted as these children were not included in the evaluation of health checking. Information on morbidity collected as part of the health check is therefore not available.

Table 2.2. Characteristics of the PEARL 1 child sample

	Mean age (range)	% Male	% Staffed home	Mean ABS ¹ score (range)	Triad of Social Impairments ² (%)	Emotional/ Behavioural Disorder ³ (%)
PEARL 1 Child Sample (n=79)	8.9 (1-17)	65.8	0.0	122.7 (12-242)	44.9	50.6

¹ ABS=Adaptive Behavior Scale (Nihira et al. 1993) - a measure of presence/absence of independent skills

² The triad of social impairments is characteristic of autism spectrum disorder (Wing & Gould, 1979)

³ Threshold score on the Developmental Behaviour Checklist ≥ 46 (Einfeld & Tonge 2002)

Twenty-seven of the 40 practices participating in PEARL 1 agreed to continue to a second phase of the research, PEARL 2, which sought to identify the extent of new unmet need identified at a subsequent health check. As this drop-out of practices was relatively high, a second recruitment strategy was implemented. There was an opportunity to involve adults who had had a health check conducted in primary care as part of the process of resettlement from two large long-stay hospitals in South Wales. Nineteen potential participants from seven practices were added from this source. A total of 139 adults who had already had a health check and a post health check audit were potentially available for this phase of the research. Four of these patients moved surgery during the study, three withdrew and a further two were withdrawn by carers, one died, 17 were excluded because the timing of the health check did not allow data collection to be achieved on time and four were excluded because of difficulties or mistakes in contacting individuals for data collection. The final achieved sample for the study comprised 108 adults.

Table 2.3 compares the characteristics of this PEARL 2 sample to those of the 318 adults for whom baseline data had been collected at the outset of the PEARL 1 study. The PEARL 2 sample was drawn disproportionately more from staffed residences than family homes or independent living than the PEARL 1 initial sample. Related to this, they had lower adaptive behaviour scores and a higher presence of social impairment and a slightly higher presence of challenging behaviour.

Table 2.3. Characteristics of the PEARL 2 sample (n=108) compared to the initial adult sample identified at the outset of the earlier phase of this research, PEARL 1

	Mean age (range)	% Male	% Staffed home	Mean ABS ¹ score (range)	Triad of Social Impairments ² (%)	Challenging Behaviour (%)	Indication of Mental Illness ³ (%)
Initial PEARL 1 Sample (n=318)	41 (17-86)	44	46	171 (14-304)	33	15	46
PEARL 2 Sample (n=108)	42 (18-80)	52	66	158 (27-293)	47	18	43

¹ ABS=Adaptive Behavior Scale (Nihira et al. 1993)

² The triad of social impairments is characteristic of autism spectrum disorder (Wing & Gould, 1979)

³ Meeting threshold levels on the Psychopathology Instrument for Mentally Retarded Adults (Matson, 1988)

Section 3: A Summary of morbidity found in the PEARL sample

3.1 Adults' data

This analysis is based on the n=190 PEARL 1 sample who received a health check. Table 3.1 shows percentage occurrence of hypertension, smoking, excessive alcohol use, significant underweight, overweight and obesity, diabetes, asthma, epilepsy, immobility, vision and hearing problems, communication problems, social impairment and autism, challenging behaviour as assessed in primary care and threshold scores indicative of mental illness.

Table 3.1 Percentage occurrence of various morbidities in the PEARL 1 sample as compared with available general population figures

	LD population	General population	LD population	
Hypertension (systolic blood pressure 140 and/or diastolic blood pressure 90 or above)	22%	30.6% ^a	Major vision problem Major or minor vision problem	12.3% 62.0%
Smoking	6.8%	25.5% ^a	Cataract	11.6%
Excessive alcohol use (14+ units/week for women, 20+ units/week for men)	1.1%	38.5% ^b	Major hearing problem Major or minor hearing problem	6.3% 19.9%
Underweight (body mass index < 18.5)	4.0% (3.9% M) (4.0% F)	N/A	Communication problem	29.4%
Overweight or obese (body mass index ≥25)	65.9% (57.1%M) (72.7%F)	60.45% ^a (65.4%M) (55.5%F)	Social impairment Triad of social impairments ¹	48% 33.7%
Obese (body mass index ≥30)	35.2% (28.6%M) (40.4%F)	22.6% ^a (22.2%M) (23.0%F)	Aggression - more than 1/mnth Aggression - more & less than 1/mnth	23.3% 32.3%
Diabetes	9.0%	3.85% ^a	Self-injury - more than 1/mnth Self-injury - more & less than 1/mnth	9.5% 12.2%
Asthma	7.9%	8.6% ^c	Overactivity - more than 1/mnth Overactivity - more & less than 1/mnth	16.8% 20.0%
Epilepsy	22.2%	0.56% ^d	Other CB ² - more than 1/mnth Other CB ² - more & less than 1/mnth	9.5% 13.2%
Immobile	4.8%	N/A	PIMRA ³ scores indicative of mental illness	43.6%

¹ The triad of social impairments is characteristic of autism spectrum disorder (Wing & Gould, 1979)

² CB = challenging behaviour. ³ Psychopathology Instrument for Mentally Retarded Adults (Matson, 1988)

^a Health Survey for England (2003)

^b Health Survey for England (2003) - % drunk > 4 units (men) or 3 units (women) in 1 day in previous week

^c Rizwan et al. (2004) - prevalence figure for parents of children with asthma

^d Currie et al. (1998) - hospital data in South Glamorgan likely to be a slight under-estimate

Commentary

Analysis of the database confirms two key domains of inequality in terms of morbidity. The first concerns the prevalence of high frequency morbidity in association with the presence of

a learning disability. This is seen in the high figures for epilepsy, behaviour disorder, sensory disorder and mobility problems. These long-term complex conditions are likely to add greatly to the inequality in health experienced by people with a learning disability.

The second domain relates to more common illnesses and conditions associated with the development of ill health. In this area the picture is in fact mixed. People with a learning disability have lower rates of smoking, alcohol usage, hypertension and asthma. (It is important to note though that comparative data on adult asthma is poor.) This is contrasted by an increase in the levels of overweight and obesity with a particular increase in those who are obese, particularly among women. The higher rate of diabetes may be linked to higher obesity.

3.2 Children's data

Data were available on a sample of 79 children who participated in PEARL I study. The data collection process differed considerably for children; health checking was not performed as there has been no move towards this in paediatric populations.

Families were asked to attend the GP and data collected on weight, height and the presence of chronic disease (this sample included 43 children). Families were also visited at home where data on the presence of behavioural disturbance was collated (this sample included 79 children). These data are seen in Table 3.2.

Table 3.2 The prevalence of morbidity in a community sample of children with learning disability

Behaviour difficulty (DBC ^a score ≥ 46)	41.8%	Abdominal morbidity	27.9%
Epilepsy	31.6%	Genitourinary syndrome morbidity	25.6%
Chronic illness	48.8%	Sensory abnormality	50.0%
Central nervous syndrome morbidity	53.5%	Obesity ^b	
Cardiovascular morbidity	14.0%	0-2 years BMI >19.3	100% (n=1)
		2-4 years BMI > 17.8	25% (n=4)
		4-9 years BMI > 21	14% (n=14)
		9 and greater BMI > 25.1	29% (n=14)

^a Developmental Behaviour Checklist (Einfeld & Tonge 2002)

^b Definition of obesity differs in childhood and relates to being over 95th percentile for each age range

Commentary

The above data confirm a high rate of morbidity in this population. The general nature of the data in most cases do not permit elaboration or comparison to normative data. However, they are indicative of the two domains of health inequality found in the adult data. There are high rates for epilepsy, behaviour disorder and sensory disorder. In addition, although based on a inadequately small sample, there is an indication of significant childhood obesity.

Section 4: Level of unmet need

As described above, 190 adults received a health check (see box on following page). The intention was then for the researchers to conduct a post health check interview with the primary care team member who had administered the health check. Given access to the medical records, the team member was able to validate whether: (a) all sections of the health check had been performed, (b) identified health needs were newly identified problems or not, and (c) action had been taken. Indicators of possible health needs found during health promotion screening were classed as health needs for the purposes of this study where they warranted some action on the part of the primary health care team. In practice, post health check interviews were conducted for 181 of the 190 people who received a health check, on average 18 weeks after it. Ninety-three of 181 individuals (51%) had health needs newly identified as a result of the health check: 59 (63%) had one health need identified, 23 (25%) two and 11 (12%) more than two. There were 147 health needs identified in total (Table 4.1): 43 (29%) arose from health promotion activities, such as a need for cervical cytology, 56 (38%) related to sensory impairment, 24 (16%) were found during the systems enquiry or physical examination and 25 (17%) fell into the remaining areas of the health check. 38 of the 147 needs identified arose through formal measurement such as mammography or blood and urine testing. The identified problems may be deemed serious for 16 patients (9% of those audited, 17% of those with newly identified health needs). These include one each with breast cancer, suspected dementia, asthma or post menopausal bleeding, two each with diabetes or hypothyroidism, and four each with high blood pressure or haematuria.

Cardiff Health Check

The primary care team asked participants to attend a health check and physical examination conducted by the doctor or nurse following the Cardiff Health Check format. In preparation for this, each practice had been given an educational resource package, as part of the study, which included chapters covering: Patient Identification; Health Checking; Causation; Nutrition; Epilepsy; Challenging Behaviour; Autism; Sensory Impairment and Using Anti Psychotic Medication.

The Cardiff Health Check followed a tick box format with 'yes' and 'no' answers in response to a series of questions on the individual's health, arranged in seven sections:

- i) Health Promotion - information on the individual's weight, height, blood pressure, urine analysis, body mass index, cholesterol level, immunization status (tetanus, influenza, Hepatitis B) and conduct of cervical screening and mammography
- ii) Chronic Illness and Systems Enquiry - information on any chronic illness (with particular reference to diabetes and asthma) and the presence of common symptoms in the respiratory; cardiovascular; abdominal; central nervous; genitor-urinary and gynecological systems
- iii) Epilepsy - information on the type, frequency and present status of epileptic seizures, current medication and any observed side effects
- iv) Behaviour - information on aggressive, self injurious, overactive or other challenging behaviour and whether this occurred more than once a month, less than once a month or infrequently
- v) Physical Examination - information on general appearance, the cardiovascular and respiratory systems, abdomen, vision, hearing, communication, mobility, dermatology, breast examination and other necessary investigations
- vi) Syndrome Specific - information on the cause of learning disability; whether chromosomal analysis had ever been conducted; the degree of learning disability; whether the patient's IQ had been tested and if a thyroid function test was indicated (i.e. if the individual had Down's syndrome)
- vii) Medication - information on all medications the individual was receiving, indicating the dosage, side effects and the levels of medication in the blood.

The health check was designed to take approximately 1 hour and the sections were ordered so that a practice nurse could complete the first half of the form and the doctor the remaining half, if this proved to be a more efficient way of conducting the health check.

Table 4.1 Previously unidentified health needs found and subsequent action

	Previously unidentified health need identified	Total cases	Management completed/in progress	No management
Potential health needs arising from health promotion screening (disease confirmed)	Glucose found in urine (Confirmed as diabetes)	4 (2)	3 (2)	1
	Thyroid function test (Confirmed as hypothyroid)	22 (2)	20	2
	Mammography indicated (Breast cancer confirmed)	1 (1)	1 (1)	0
Problems with behaviour, medication and other	Suspected dementia	1	1	0
	Behaviour problem	1	1	0
	Mobility problem	5	5	0
	Skin problem	12	12	0
	Dental problem	1	1	0
	Medication change necessary	2	2	0
	Medication blood levels to be monitored	2	1	1
Problems with sensory impairment	Overweight	5	3	2
	Vision difficulties	7	7	0
	Eye infection	1	1	0
	Hearing difficulties	2	2	0
	Blocked ear wax	46	41	5
Respiratory system	Ear canal inflamed (otitis externa)	1	1	0
	Asthma	1	1	0
	Difficulty breathing (dyspnoea)	1	0	1
Cardiovascular system	Unusual lung sounds	1	1	0
	Cardiovascular monitoring necessary	1	1	0
	Systolic murmur	2	2	0
	High blood pressure	4	4	0
Digestive system	High cholesterol	3	3	0
	Disordered digestion (dyspepsia)	1	1	0
	Weight loss	1	1	0
	Constipation	3	3	0
	Diarrhoea	1	1	0
	Flatulence	1	1	0
Genito-urinary system	Haemorrhoid	1	1	0
	Painful urination (dysuria)	1	0	1
	Incontinence	2	1	1
	Urinary tract infection	4	4	0
Gynaecological	Blood found in urine (haematuria)	4	4	0
	Post menstrual bleeding	1	1	0
	Painful menstruation (dysmenorrhoea)	1	1	0
Total number of medical problems identified		147	133	14

Management had been initiated for 90% of the identified health needs by the time of the audit (Table 4.1). Treatment had been concluded for 61% of the 133 health needs concerned and was ongoing for the remaining 39%. In some of the 14 instances (10%) where management had not occurred, patients or carers had refused treatment; in others treatment delays had occurred due to difficulties in pursuing treatment or other external factors.

Commentary

These results come from the first study to evaluate the impact of health checking in a large UK primary care population. The sample was identified from primary care practices which served approximately one eighth of the population of Wales. The study found unidentified health problems in over half of the sample and serious illness in a significant proportion (9%). It is also a testament to the value of structured health checks that about a quarter of the health needs identified arose through the type of formal measurement which is difficult to achieve opportunistically.

While the significance of detecting serious illness is self-evident, it is important to note that the other conditions more commonly found, such as vision and hearing difficulties and blocked ear wax, may be more significant for people with intellectual disabilities than the general population through their impact on already limited social, communicative and practical abilities.

Section 5: Level of unmet need at a subsequent health check

In the PEARL 2 study, those adults who had a health check during the PEARL 1 research were randomly allocated to two equal groups. Group A were to have a repeat health check (at T_1) as a follow-up to the one already received as part of the PEARL 1 research (at T_0), while Group B were to wait without their health being checked. About a year later, Group A received a further, final health check (at T_2) and Group B received their first repeated health check (at T_2). After the loss of participants described above which reduced the sample to 108, there were 50 in Group A and 58 in Group B.

However, health checks were not conducted for all participants as planned, either due to the participants missing appointments or the primary care team overlooking to perform the check. At T_1 , 39 adults in Group A had the first repeated health check. At T_2 , 30 of these 39 adults in Group A received the final health check, and 36 in Group B had a first repeated health check. Eleven participants in Group A and 22 in Group B did not have a health check at any time. For the purposes of investigation of the impact of health checking, analyses have therefore examined three groups: Group 1 - 39 people in Group A who received the first repeated health check at T_1 , Group 2 - 36 people in Group B who received their first repeated health check at T_2 , and Group 3 - 33 people in Groups A or B not receiving a health check at either T_1 or T_2 . For some analyses, a fourth group (Group 4) was considered, namely those 30 adults in Group 1 who received a final repeated health check at T_2 .

Table 5.1 compares the characteristics of Groups 1-4. It can be seen that compared to Group 1, Group 2 had higher proportions of males and participants who lived in staffed housing, were socially impaired, had challenging behaviour and reached threshold levels indicative of mental illness. Ages and adaptive behaviour scores were similar. Group 3 had a higher presence of social impairment and threshold levels for mental illness and lower adaptive behaviour scores than Groups 1 and 2, indicating that those who did not receive a health check had slightly lower adaptive behaviour and greater socially impairment and mental health problems. Group 4 were a subset of Group 1, who had a second repeat health check. They had higher adaptive behaviour scores and a lower presence of problems indicative of mental illness. Consistent with the comments about Group 3 above, therefore, those in Group 1 who did not receive a second health check tended to have lower adaptive behaviour scores and greater indications of mental illness.

Table 5.1 Characteristics of Groups 1 (n=39), 2 (n=36) and 3 (n=33), and Group 4 (n=30)

	Mean age (range)	% Male	% Staffed home	Mean ABS ¹ score (range)	Triad of Social Impairments ² (%)	Challenging Behaviour (%)	Indication of Mental Illness ³ (%)
Group 1 (n=39)	41 (21-73)	44	59	167 (35-293)	37	15	39
Group 2 (n=36)	43 (21-80)	56	78	164 (56-290)	50	19	44
Group 3 (n=33)	44 (18-67)	58	61	143 (27-289)	55	19	48
Group 4 (n=30)	40 (21-73)	50	53	181 (38-293)	35	13	33

¹ ABS=Adaptive Behavior Scale (Nihira et al. 1993)

² The triad of social impairments is characteristic of autism spectrum disorder (Wing & Gould, 1979)

³ Meeting threshold levels on the Psychopathology Instrument for Mentally Retarded Adults (Matson, 1988)

The time interval between the initial and first repeated health checks for Group 1 averaged 28 months (range, 16-39 months). The time interval between the initial and first repeated health checks for Group 2 averaged 44 months (range, 31-54 months). The time interval between the first and final repeated health checks for those in Group 1 who received both repeat health checks (i.e., Group 4) averaged 14 months (range, 7-20 months).

The means and ranges for the numbers of new health needs identified at the baseline (T_0), intermediate (T_1) and final health checks (T_2) for the relevant groups are given in Table 5.2. All means were either just under (at T_0) or over (at T_1 and T_2) one. There were no within or between group differences revealed in any of the analyses undertaken. The slightly higher mean number of new health needs identified at T_1 and T_2 compared to T_0 was associated with lower proportions being identified as having no health needs. Otherwise the distribution of finding one to five health needs was fairly similar. The correlation between number of new needs identified at the first repeated health check and the interval between that and the baseline health check ($\rho = -.07$) was not significant (see Figure 5.1).

Table 5.2 Mean numbers (ranges) of new health needs identified for Groups 1-3 (and Group 4) at the three time points (T_0 , T_1 , T_2)

	Baseline (T_0)	Intermediate (T_1)	Final (T_2)
Group 1 (n=39) [Group 4] (n=30)	.95 (0-5) [1.0 (0-5)]	1.28 (0-5) [1.20 (0-5)]	- [1.20 (0-3)]
Group 2 (n=36)	.92 (0-5)	-	1.14 (0-5)
Group 3 (n=33)	.93 (0-3)	-	-

Figure 5.1 Scatterplot of number of needs identified at the first repeat health check against the interval (months) between it and the baseline health check

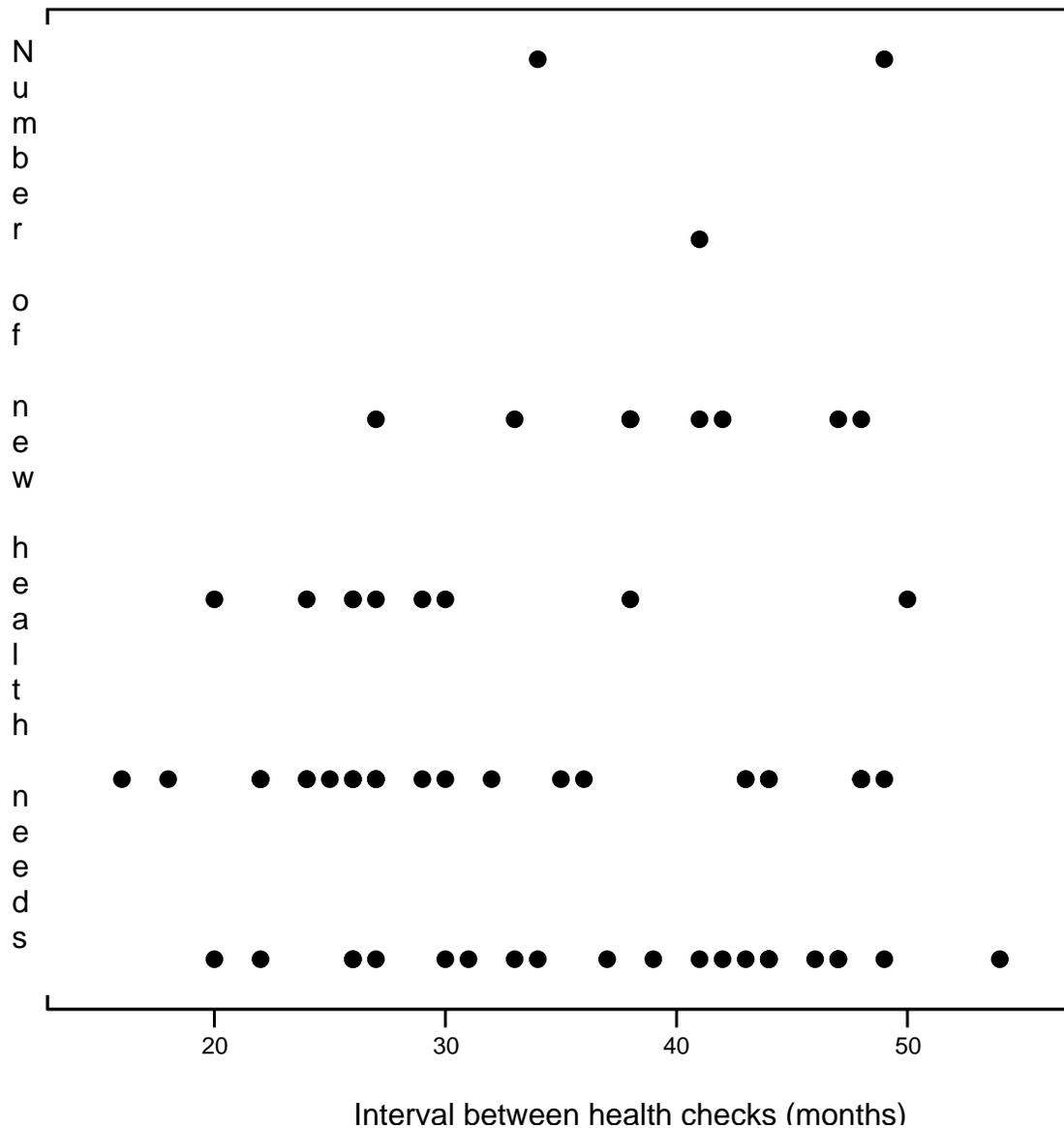


Table 5.3 Nature of new health needs identified for Groups 1 and 2 at baseline health check (T₀) and at the first repeated health check (Group 1: T₁, Group 2: T₂) and the final health check for Group 4 (T₂)

	Nature of new health need	Group 1 (n=39)		Group 2 (n= 36)		Group 4 (n=30)
		T ₀ health check	T ₁ health check	T ₀ health check	T ₂ health check	T ₂ health check
Potential needs arising from health promotion screening	Glucose found in urine		1	2		
	Thyroid function test	6	4	4	4	5
	Breast lump				1	
Problems with behaviour, medication and other	Suspected dementia					
	Behaviour problem					
	Mobility problem			1		
	Skin problem	2	7	3	3	5
	Dental problem			1		
	Medication change necessary	1				
	Medication blood monitoring	1				1
	Other haematological test	1	1	1	2	3
Problems with sensory impairment	Overweight	3	2	1	1	
	Vision difficulties	1		1	1	1
	Eye infection					
	Hearing difficulties	2		1		
	Blocked ear wax	7	3	10	5	6
	Ear canal inflamed (otitis externa)	1		1		
	Referral to optician	1	2		3	1
Respiratory system	Otitis media (ear infection)		1			
	Referral to speech therapy					1
	Asthma					
Cardiovascular system	Difficulty breathing (dyspnoea)					1
	Unusual lung sounds			1		
	Swelling of ankles					
	Systolic murmur			1	1	
Digestive system	High blood pressure	1	1	2	1	
	High cholesterol/cholesterol checked	1	1			2
	Disordered digestion (dyspepsia)	1			1	
	Weight loss				1	
	Constipation					
	Diarrhoea				1	1
Genito-urinary system	Feeding problem		1			
	Bleeding PR		1			
	Painful urination (dysuria)			1		
	Prostate difficulty				1	
	Incontinence/nocturia		2	1	2	1
Gynaecological	Urinary tract infection/abnormal urine		1		4	
	Blood found in urine (haematuria)	1				
Health promotion	MSU indicated		1			
	Post or Inter menstrual bleeding		1			
	Painful menstruation (dysmenorrhoea)	1				
	Tetanus Immunisation	2	2		3	1
Health promotion	Flu vaccine	2	7		6	2
	Smear needed	1	5			2
	Hepatitis vaccine		3			
Total number of medical problems identified		36	47	32	40	33

The nature of new health needs identified for Groups 1 and 2 at the baseline and first repeated health checks, and for Group 4 at the T₂ health check, is set out in Table 5.3. It can be seen that there were a greater number of health promotion measures per person taken at the later health checks, an increase which accounted for the increase in health need identification overall. Otherwise the new health needs identified at the repeat check were broadly similar to those identified at baseline.

Commentary

At least within the intervals between checks investigated here, there was no reduction in their utility in identifying previously unidentified health need. Nor was there an indication that the number of new health needs being identified at a health check was related to the interval between health checks. Average intervals between health checks were all above 12 months, with the interval between the first and second repeated health check for Group 4 being the lowest (14 months). The results here would, therefore, suggest that annual health checks are justifiable if health checking is to be undertaken.

The slightly higher identification of health needs at the repeat health checks compared to the initial one appeared to stem from a greater attention to health promotion, an area of known underperformance with respect to people with learning disabilities. This may indicate a growth in experience of the primary care teams undertaking the health checks. Otherwise, the nature and distribution of health needs identified was similar at the first repeat check to those found at the initial check. As reported above, 93 out of 181 individuals (51%) had health needs newly identified as a result of the PEARL 1 health check, of whom 16 had problems identified which may be deemed serious (including one each with breast cancer, suspected dementia, asthma or post menstrual bleeding, two each with diabetes or hypothyroidism, and four each with high blood pressure or haematuria). In the current study, 51 out of 75 (68%) had health needs newly identified as a result of the first repeat health check, of whom 8 had problems identified which may be deemed serious (including one each with a breast lump, diabetes, weight loss, prostate difficulty, or post or inter-menstrual bleeding and two with high blood pressure). On this basis, we have concluded that health checking is an effective intervention for identifying remediable general health problems among people with learning disabilities. Health needs can be identified among adults with a learning disability who may fail to report symptoms due to restricted communication or social or other impairments, and appropriate health promotion undertaken, through the use of structured health checks. Following the conclusion above, we would argue that annual health checking is justifiable.

Despite this general conclusion, gaining commitment to providing the additional time and resources to conduct the health check cannot be assumed. Nor can one be sure that individuals will keep appointments so that health checks can be performed. 13 of the 40 practices which had participated in the PEARL 1 research were unable or unwilling to collaborate further. Moreover, health checks were not conducted for 33 of the 108 participants and a further 9 of the 39 participants in Group 1 who had a health check at T₁ did not have another at T₂. Overall, only 61% of participants had health checks according to the planned schedule. There appeared to be a number of factors influencing whether health checks were conducted. For example, four of the five participants who lived independently did not have a repeat health check, perhaps due to having less support to attend the surgery than people living with carers. In addition, excluding these five participants, those not receiving a health check at T₂ had significantly lower ABS scores than those who did ($z=-2.755$, $p<.01$). Particular effort will need to be made to make sure that people have equality of access to effective care across the ability spectrum, wherever they live.

Section 6: Access to health promotion

In this section we analyse a subsection of the PEARL 1 dataset to assess the frequency of uptake of health promotion actions in a primary care identified population of adults with a learning disability. We describe the pattern of the following health promotion activities and explore the relationship between the level of disability and health promotion uptake:

1. Cervical Cytology
2. Mammography
3. Blood pressure screening
4. Weight recording
5. Height recording
6. Recording of smoking and alcohol use
7. Cholesterol measurement
8. Urine testing
9. Immunisation

Data on health promotion was collated from general practice notes for a period of two years prior to the recruitment of the PEARL 1 sample for those individuals whose general practice was within the former Bro Taf health region of South Wales. This subsample was chosen because of the availability of health promotion norms for the population as a whole. Routine health data provided from Bro Taf Health Authority and Breast Test Wales provided control data for cervical cytology and mammography.

Control data for blood pressure height, weight, smoking, drinking and urine testing were drawn from published literature where available.

A total of 22 practices in Bro Taf were included in the PEARL 1 dataset. Data from Bro Taf Health authority were available on 21 of these practices, including Townsend deprivation scores. The 21 practices with practice population figures available had a total population of 151,000. A total of 106 patients provided the sample for the study. The patients had a mean age of 35 years with a range of 3 to 86 years. Sixty (57%) were female and 21 were under 18 years of age. Based on estimated conversion from Adaptive Behavior Scale scores (Nihira et al. 1993), 18 (17%) were categorised as having a mild learning disability, 51 (48.1%) a moderate learning disability and 37 (34.9%) a severe or profound learning disability.

6.1 Cervical screening

A total of 55 patients were eligible for cervical cytology. Seven of these (12.7 %) received cervical cytology in the two years prior to data collection. Control data on average cervical

cytology rates is seen in Table 6.1. The average take up of cervical cytology in the participating practices was 84%.

12 patients with a mild learning disability were eligible for cervical cytology and 4 of these (33%) had cytology performed. 25 had a moderate learning disability and 3 of these (12%) had cytology performed and 18 had a severe learning disability none of whom had cytology performed.

Table 6.1 Practice data for deprivation, cervical cytology, immunisations and consultation rates

Practice Code	Population	Townsend Deprivation Score	Cervical cytology uptake (%)	Immunisations per 1000 per year	Consultations per 1000 per year
3	6517	2.2	85	70	N/A
9	1339	5.2	91	285	4538
11	9693	0	87	183	4925
12	4804	4.7	85	115	6153
13	5029	1.2	82	97	3457
14	8090	2.8	80	48	4326
15	15431	-2.5	87	70	5316
17	3711	0.3	89	64	3711
19	5033	2.0	91	91	N/A
22	1606	4.6	69	N/A	2134
24	3460	3.8	71	19	4399
25	8416	4.1	83	50	4580
26	5087	-0.5	88	120	N/A
28	15856	1.2	80	69	3739
29	3924	1.4	85	114	4148
31	12716	-3.3	88	102	N/A
32	7932	0.8	83	109	3403
33	12641	5.2	82	61	5975
35	10777	-1.3	89	76	3570
36	5538	2.6	86	89	3788
37	3796	2.6	88	78	4106

6.2 Mammography

A total of 15 individuals in the study were eligible for mammography being aged 50 years or over. A total of 4 of these (26%) received a mammogram in the preceding two years.

Control data were not available from within practices. However, comprehensive data on the uptake of mammography was obtained from Breast Test Wales. The uptake of mammography is closely influenced by the deprivation indices in an area. Percentage uptake of mammography in Bro Taf ranged from 40-44.9% in areas of high deprivation (Townsend scores 10-14) to 80–84.9% in areas of low deprivation (Townsend scores 5 - -9). As data from Breast Test Wales were available on individual wards within Bro Taf, it was possible to calculate an average mammography take up for the participating practices controlled for relative deprivation. The 26% rate for people with a learning disability should be compared with a 71% rate for the practice populations as a whole.

Four of the 15 eligible patients had a mild disability and 2 of these (50%) had mammograms, 6 had a moderate disability and 2 of these (33%) had mammograms and 5 had severe disability and none of these had mammograms.

6.3 Blood pressure screening

A total of 85 adults were eligible for regular blood pressure screening. Within the two years prior to the study, 36 (42%) received blood pressure measurement. Published data (Kerr et al., 1996) shows a figure of 46% for blood pressure measurement in the general population. 17 individuals with a mild learning disability were eligible for blood pressure screening and 14 of these (82%) received blood pressure measurements. 42 individuals had a moderate disability and 13 of these (30%) received blood pressure measurement. 26 individuals had a severe learning disability and 9 of these (35%) received blood pressure measurements.

6.4 Weight recording

Over the two-year data recording period, 23 individuals (27%) had their weight recorded. 17 individuals with a mild disability were eligible for weight recording and 6 of these (35%) had their weight measured. 42 individuals with a moderate disability were eligible and 13 of these (31%) had their weight measured. 26 individuals with a severe learning disability were eligible for weight recording and 4 of these (15%) had their weight measured.

6.5 Height recording

Over the two-year data recording period, 12 individuals (14%) had their height recorded. 17 individuals with a mild disability were eligible for height recording and 2 of these (12%) had their height measured. 42 individuals with a moderate disability were eligible for height recording and 8 of these (19%) had their height measured. 26 individuals with a severe learning disability were eligible for height recording and 2 of these (8%) had their height measured.

6.6 Smoking

11 individuals (13%) had their smoking history recorded: 3 of the 17 people with a mild learning disability (17%), 3 of the 42 people with a moderate learning disability (7%) and 2 of the 26 people with a severe learning disability (8%).

6.7 Alcohol Use

10 individuals (26%) had their drinking history recorded: 4 of the 17 people with a mild learning disability (24%), 4 of the 42 people with a moderate learning disability (8%) and 2 of the 26 people with a severe learning disability (8%).

6.8 Cholesterol measurement

One individual had a cholesterol level measured in the two-year period; this individual had a moderate learning disability.

6.9 Urine testing

13 individuals (15%) had their urine tested: 1 of the 17 people with a mild learning disability (6%), 8 of the 42 people with a moderate learning disability (19%) and 4 of the 26 people with a severe learning disability (15%).

6.10 Immunisations

23 out of 106 individuals (22%) had an immunisation procedure performed: 2 of the 18 people with a mild learning disability (11%), 11 of the 51 people with a moderate learning disability (22%) and 10 of the 37 people with a severe learning disability (27%).

6.11 Impact of level of disability

Table 6.2 summarises the relative percentage of uptake of all the health promotion measures in relation to level of disability.

Table 6.2 The percentage of uptake of all the health promotion measures related to level of disability

Health Promotion Activity	Mild learning disability (% uptake)	Moderate learning disability (% uptake)	Severe learning disability (% uptake)
Cervical cytology	33	12	0
Mammography	50	23	0
Blood pressure measurement	82	30	35
Height recording	12	19	8
Weight recording	35	31	15
Smoking history	17	7	8
Drinking history	24	10	8
Immunisations	11	22	27
Urine testing	6	19	15
Cholesterol	0	1	0

Commentary

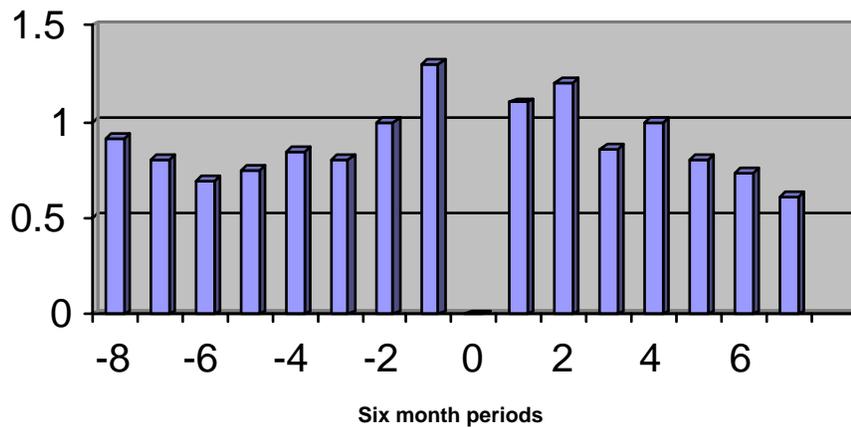
This analysis showed a clear difference in health promotion uptake for a primary care identified population of individuals with a learning disability. People with a learning disability had reduced cervical cytology and mammography as compared with population norms. Blood pressure monitoring was the only health promotion measure to approach population norms. Figures for immunisations, height recording, weight recording, recording of smoking and drinking and cholesterol measurement were all low.

The clearest influence of health promotion uptake from level of disability could be seen in the areas of women's health. This may be an appropriate outcome for cervical cytology where women with severe learning disability are less likely to be sexually active, although it is important not to make generalised assumptions about who is or is not sexually active. However, this same factor would constitute a risk factor for breast cancer increasing the case for mammography.

Section 7: Frequency of contact with primary and secondary care

Information on the frequencies of contacts with specialists (including specialists in learning disabilities), health promotion actions and general practice consultations was collected for 77 of the 108 PEARL 2 sample. Fig 7.1 shows the average number of contacts with specialists in 8 six month periods before and 7 six month periods after the first (PEARL 1) health check. There was no difference in rate of contact before and after the first health check. The overall mean frequency of contact was 0.89 (i.e., 1.78 per year).

Figure 7.1 Mean number of contacts with specialists during consecutive six month period four years before and three and a half years after the first health check



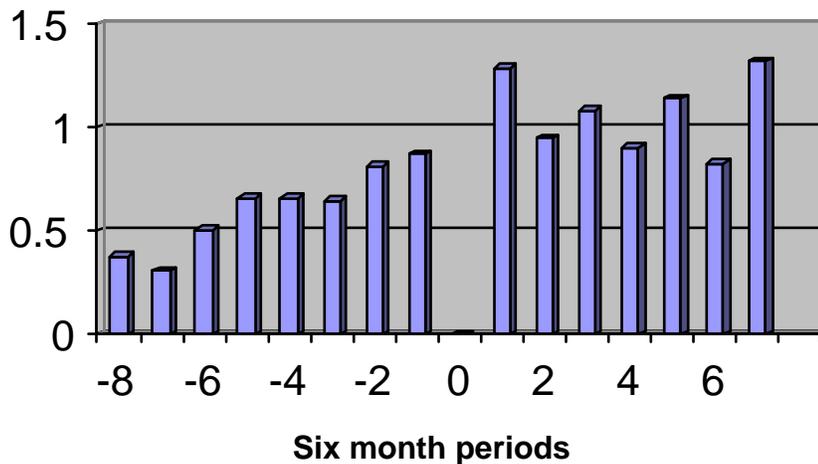
■ Mean number of contacts with specialists

In all time periods, the majority had zero contacts (mean 55%, range 38-64%) and about half of the remainder had one specialist contact (mean 25%, range 15-39%). The maximum number of contacts per person in a six month period ranged between 4 and 9 (mean 7.5). Across the entire period, 4.3% never saw a specialist, 37.1% saw a specialist less frequently than once a year, 22.9% saw a specialist between once and twice a year and 36.7% saw a specialist more than twice a year.

Fig 7.2 shows the average number of health promotion actions in 8 six month periods before and 7 six month periods after the first (PEARL 1) health check (NB health promotion actions conducted within this and subsequent health checks were excluded) . The frequency of

health promotion actions rose after the first health check from a mean of 0.6 (i.e., 1.2 per year) to a mean of 1.1 (i.e., 2.2 per year).

Figure 7.2 Mean number of health promotion actions during consecutive six month period four years before and three and a half years after the first health check



■ Mean number of health promotion actions

In all time periods before the first health check, about three-quarters of individuals had zero contacts (mean 74%, range 70-82%). This reduced to below two-thirds after the first health check (mean 62%, range 57-65%). The maximum number of contacts per person in a six month period ranged between 5 and 24 prior to the first health check and between 8 and 23 afterwards. Across the entire period, 5.6% received no health promotion actions, 51.3% had fewer than one health promotion action per year, 22.3% received between one and two health promotion actions per year and 20.8% received more than two health promotion actions per year.

Figure 7.3 shows the average number of consultations with the GP or another member of the primary care team (henceforth termed 'GP consultations') in 8 six month periods before and 7 six month periods after the first (PEARL 1) health check. The frequency of GP consultations rose towards the first health check, remained relatively high for the next two years and then declined in frequency. There was no difference between the two halves. The overall mean was 2.7 (i.e.,

5.4 per year). This can be compared to a weighted average of 4.4 consultations per year for the practices listed in Table 6.1.

In all time periods before the first health check, between a quarter and a half of individuals did not have a GP consultation (mean 33%, range 25-47%). This was reduced to between a fifth and a third after the first health check (mean 28%, range 17-37%). The maximum number of contacts per person in a six month period ranged between 9 and 27 prior to the first health check and between 15 and 22 afterwards. Across the entire period, there was no-one who did not see the GP at least once. 6.8% saw the GP on average less than once a year, 15.5% saw the GP between once and twice per year, 37.0% saw the GP between twice and four times per year, 18.1% saw the GP between four and eight times per year, and 21.9% saw the GP more than eight times per year.

Figure 7.3 Mean number of GP consultations during consecutive six month period four years before and three and a half years after the first health check

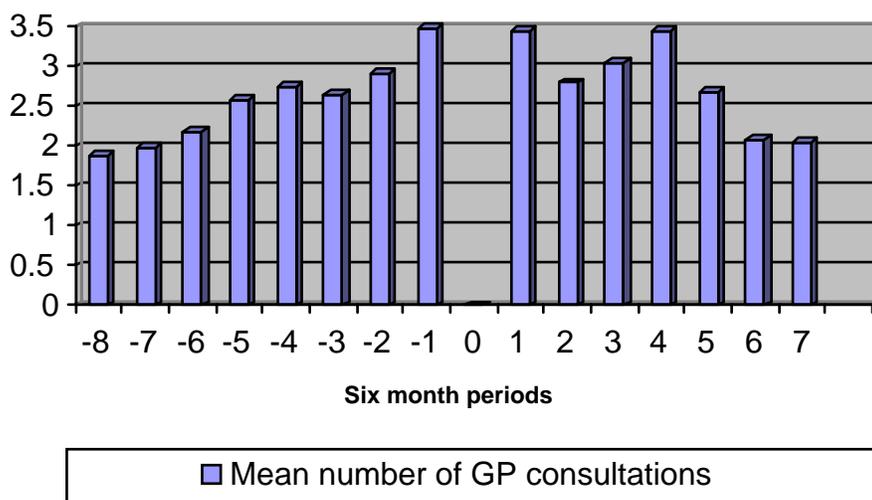


Table 7.1 summarises the frequency of occurrence of contact with specialists, health promotion actions and GP consultations before and after the first health check, broken down by Group. Group 1 had a repeated health check on average 28 months after the first health check (range, 16-39 months), and the majority had a second repeated health check an average of 14 months later (range, 7-20 months). Group 2 had a repeated health check on average 44 months after the first health check (range, 31-54 months). Group 3 did not have a subsequent health check.

One would expect that any impact of health checking would be seen by a greater increase among Group 1 than in Groups 2 and 3. Table 7.1 shows unsystematic variation in relation to the frequency of contacts with specialists and GP consultation rates. However, there is a greater discernable pattern in relation to the frequency of health promotion actions. The increase is greatest for Group 1 and may be related to the greater frequency of health checking.

Table 7.1 Annual rates of contact with specialists, health promotion actions and GP consultations during consecutive six month period four years before and three and a half years after the first health check for three Groups: Group 1 who had two further health checks, Group 2 who had one further health check towards the end of the period and Group 3 who had no further health checks

	Group 1		Group 2		Group 3	
	Before HC	After HC	Before HC	After HC	Before HC	After HC
Contact with Specialists	1.4	2.1	2.3	1.7	1.2	1.7
Health Promotion Actions	1.4	3.4	1.0	1.5	1.3	1.7
GP Consultations	3.6	4.1	6.9	6.0	4.8	7.3

Commentary

Access to services is central to the principle of equality of health care. Measuring access poses certain difficulties and these are reflected in the data here. Access should relate to the specific services needed arising from the health status of the individual.

Specialist health contact is common for people with a learning disability. However, it is difficult to say from the data presented here whether an inequality exists. It is clear that variation exists in specialist contact within the learning disability population but it is not known whether the variation found is more than would be reasonable given the variation in morbidity among the population. Further research is needed to show whether patients with a learning disability are referred at the same time in their health journey as the general population and to illuminate the

balance in referrals between those concerning conditions closely associated with learning disability and those concerning generic ill health.

Inadequate access to health promotion seems likely to be a major underlying factor in the inequality in health among people with a learning disability. The analysis in Section 6 has already illustrated disparity across a range of health promotion measures. These data reinforce the message about inadequate health promotion delivery and also provide a picture of the variability in health promotion received. In every six month period in the three years prior to having a health check, three quarters of the sample had had no contact for health promotion procedures. The majority received fewer than one health promotion action per year across the entire 7.5 years, although a minority received a significantly higher rate. The data are also consistent with the analysis in Section 5 indicating that health checking appears to increase health promotion contacts over and above those conducted within the health check. This means that GPs involved in health checking have undertaken more health promotion in addition to the routine health promotion measures performed during the health check.

GP consultations may act as a proxy measure of the accessibility of primary care for people with a learning disability. Kapur et al. (2005) showed ranges for annual GP consultation of 2-7 for females and 2-4 for men. The weighted average annual consultation rate for the general population in the practices in the Bro Taf area was 4.4. Compared to these norms, the data here are in agreement with other published data (e.g., Stein & Ball, 1999) that there is not a deficit in the average rate of contact with general practice among people with learning disabilities relative to the general population. The concern remains, however, that there is a deficit in the level of contact relative to the high health needs of this specific population. In relation to this, it is perhaps more relevant to compare consultation rates with patients with a chronic condition rather than to the general population. Morgan et al. (2000) showed that the annual mean number of consultations with either a general practitioner or other member of the practice staff for patients with diabetes was 18.5 compared with 5.7 for those without. The slightly higher rate of GP consultations found here compared to the average for people in the general population would appear to be insufficiently greater given such a comparison.

Section 8 : An investigation into the experiences of people with mild learning disabilities when visiting their doctor's surgery

This section of the report is based on five focus groups conducted with adults with learning disabilities able to understand the purpose of the inquiry and articulate their views, albeit with help in some cases from personal supporters.

The five focus groups were organised by All Wales People First in a similar way to how they had organised consultations on Welsh Assembly Government policy statements in recent months. They were held in south, west, mid, north west and north east Wales and were attended altogether by 63 people with learning disabilities¹, who were able to understand the nature of the inquiry and give consent to their views being subsequently reported anonymously. Participants had been notified of the consultation by All Wales People First using their usual mailing network and advertisements in service settings. The focus group meetings ranged in attendance from 7 to 15. Each meeting was facilitated by a number of people familiar with supporting self-advocates so that small discussion groups could be formed. Discussion groups ranged in size from 3 to 7 people with learning disabilities. Participants chose to form the discussion groups along friendship lines. First language preference was checked at the beginning of each meeting but only participants in the north west Wales consultation chose to use Welsh and English bilingually throughout the discussion. The remaining meetings were transacted in English by the choice of all the delegates. All comments were recorded in English on one flip chart for each discussion group but care was taken in the bilingual meeting to ensure that statements written in English were acceptable to participants making their views known in Welsh.

Each meeting took place between 10.15 a.m. and 3.00 p.m. and followed a similar agenda (see topic list in the box on the following page). Participants were given an explanation sheet in clear language and using a large font size a fortnight in advance. Following arrival and refreshments, the researcher (JF) introduced the meeting organisers and the participants to each other and used a clear language script to go over the purpose of the meeting. She then asked people to sign consent forms to give permission for the reporting of their anonymised views. Participants were reassured that there could be a break in proceedings if for any reason they became upset. Then in three periods of about 55 minutes each, interspersed by a 15-minute break and a 40-minute period for lunch, the groups discussed the topics of "Getting to see the doctor", "Communication issues" and "Being healthy". Each 55 minute period was divided into 45 minutes when topics were discussed freely in small groups and views written up on flip charts

and 10 minutes during which each group's recorded comments were read to everyone in plenary. The meeting ended by a final drawing together in plenary of suggestions for "What would make things better?" (approx 35 minutes). Throughout, it was made clear that it was only the views of participants with learning disabilities that would be formally recorded on the flip charts. However, parents and other supporters were reassured that their views were valued and could be reported separately. Notepads were distributed in which accompanying supporters could write down their views if they wished. Opinions expressed in this way are included in Appendix 1.

Question prompts for sessions (use only if necessary)

Session 1 Getting to see the doctor

If you think you need to go to the doctor what do you do? What happens?

Do they help you get an appointment easily?

Are they good at referring you on for further tests or treatment if you need it?

What happens if the doctor says you have to go to a specialist?

Session 2 Communication issues

Are they good at listening to you?

Are they good at talking to you?

Do you ever talk to the nurse for a little while before you go in to see the doctor and do you think this is/would be a good idea?

What happens if the doctor says you have to go to a specialist?

Session 3 Being healthy

Doctors' surgeries are also there to help people keep healthy: do you have regular check-ups, e.g. for blood pressure or to be weighed?

Do they give you useful health advice?

Session 4 What would make things better?

What other good experiences have you had using your GP surgery/local health centre?

What helps you most?

How you think your GP surgery/local health centre could work better for you?

¹ Some participants were accompanied by supporters. Supporters have not been included in the total attendance.

The results are presented under the three headings: Getting to see the doctor, Communication issues and Being healthy. Suggestions made in the fourth session about what would bring improvements are integrated within these sections as discussion in this session mainly pooled and confirmed the importance of points already made.

8.1 Getting to see the doctor

8.1.1 Arranging to see the doctor

Participants had mixed experiences in making appointments to see the doctor or another member of the primary care team. Some did so independently by telephone and reported that this worked well.

I ring - it's very easy - I make the call myself.

I phone the doctor - I've got the number at home - I can see the doctor or nurse at the same time.

However, most found ringing for an appointment was difficult and off putting. Some said that they would prefer to do it themselves but asked a relative or carer to do it for them because they felt that the process of getting through to the surgery and negotiating with the receptionist was daunting. Some people solved the problem of using the phone or having to ask someone else to ring on their behalf by choosing to visit the surgery and making the appointment face to face.

Sometimes it's difficult to get an appointment.

The telephone lines are busy.

For someone who has difficulties explaining things, it is easier for someone else to make the appointment.

One person from Health Advocacy project who would make her own appointment, phoned receptionist who didn't listen, hurried her along, finished her sentences, so she decided she wouldn't do it again. (Note: this was the experience of someone not at the meeting reported by one of the participants.)

I would like to ring the surgery myself. (Note: at the moment his support worker does this for him.)

Go to the surgery and make appointment face to face.

Difficulties in phoning were compounded by technology which participants found complicated and frustrating (such as menu systems driven by touch tone responding) and the perseverance needed to get through during peak or required times for making an appointment. Participants also experienced variation in how long they had to wait for an appointment, which undermined their confidence. They complained about receptionists deciding whether their need for an appointment was an emergency or not. Although some participants praised receptionists for being helpful, others found them difficult to deal with. In particular, they disliked being

interviewed by the receptionist about the nature of their ailment or problem prior to being able to gain an appointment.

To contact the triage nurse, I need to go to the answerphone menu.

I like to call the surgery and speak straight to the receptionist – don't like 'touch tone' phones.

The recorded music on the phone which we phone up is very hard when we have to keep waiting.

The receptionist takes a long time to call.

It's hard to get an appointment, (they) don't answer the phone and then (you) have to wait weeks for an appointment.

Don't always get a same day appointment. Sometimes you have to wait for up to 2 weeks.

Receptionist asks if it is an emergency, they usually decide whether it is urgent based on what they are told.

It would better if they didn't say 'is it an emergency?' because that's upsetting.

(On receptionists) ... Some are very helpful. Some are not good at communicating i.e. they don't always seem to be listening. I feel that they don't take us seriously.

Receptionist and triage nurse are asking personal questions - don't want to speak to nurse want to speak to doctor - no chance for privacy - personal problems become public.

Put simply, participants

Would like a simple straight forward way to make an appointment.

8.1.2 Out of hours service

There was considerable variation in organisation of out-of-hours services. In general, the within hours difficulties in arranging to see the doctor described above were exacerbated at night and at weekends. Sometimes the out-of-hours service was so inconvenient, that people found it easier or were directed to use another service, such as the local hospital. Sometimes, the central call arrangements could take a long time (one hour or more) to contact the doctor and phone back with further information. There were particular difficulties in rural areas, where journey times could be long if one on-call doctor covered a large area.

It's always easier in the day time for people to be independent when they're not well.

It kept ringing and no-one answered (out of hours) for a long time.

No one came to visit – told me to take tablets on the phone. He didn't know me. They should have come to see me. They didn't know what was wrong on the phone.

However, participants also gave examples of services being responsive.

I was ill in the evening mum rang. She asked for the nurse and she came. It was good to have a nurse she asked me questions. It made me feel better. She understands how I felt.

8.1.3 Choice of doctor

Participants appreciated being able to choose their doctor and to develop a relationship over time. Many felt that they did see the doctor that they wanted to see.

The doctors are friendly they do make you welcome.

Got to know doctor well.

It is better when they know me.

It is better to always see your regular doctor.

I have a man and a woman - they are good at listening.

I see two doctors - don't mind either.

However, some experienced problems in choosing or changing their doctor, there was not always the possibility to have a female doctor, and some participants felt that they could not develop a consistent relationship with a doctor who regularly saw them.

Don't have a choice of doctor or surgery

You have to have which doctor you're given.

Never know who you are going to see. So many different ones.

Anything can happen.

No chance of seeing named doctor.

It's difficult if I have another doctor when my doctor's not there.

Don't have chance to get to know them or for them to know you.

It all depends on which doctor you see.

A good thing would be a choice of male or female doctor.

No women doctors at my surgery – have to see a man.

There are no lady doctors.

I would like to change doctors if I had my way.

I tried to change my doctor who is a man. The receptionist said I couldn't. I'd prefer a female doctor to talk about female things. I was told I couldn't change.

8.1.4 Being at the surgery

Although participants recognised that surgeries often had magazines and sometimes television programmes to watch, the waiting environment was generally criticised. Some people were routinely given convenient appointments and rarely waited for a long time.

Mostly they see me quickly.

I have to wait only a few minutes.

However, people who attended other surgeries normally expected to have to wait and waiting times were criticised. Participants described themselves as already nervous when going to see

the doctor and that waiting made it worse. Something to take their mind off waiting would have improved the situation. In addition, participants were sometimes disappointed if the arrangements that had been made were not fulfilled, or if they had not been told about alterations to what they expected to happen.

Sometimes I have to wait a long time in the reception and they are long time calling my name.

Sometimes I need to wait all morning, especially busy days (Mondays).

Read a magazine – don't like it much.

Very boring waiting.

It's a rough time - can wait up to 1 hour.

Advertising TV not very good.

Instead of ads there could be programmes.

Could have a café there.

Have a cup of tea.

Do something take mind off waiting.

Suffer epilepsy – just sitting in surgery not interested in magazines.

It would be handy if they could get to work on time. We waited for 45 minutes, she didn't apologise. It would be good to have an apology if people are late and an explanation.

Sometimes doctors not available (in spite of earlier arrangement) (e.g., due to holidays, sickness).

Participants appreciated systems which made it very clear to them when to go into the doctor. Some people liked visual displays very much. However, it was recognised in discussion that these would not be helpful to people who could not read. Some surgeries had number systems to denote when a person's turn had come. Others relied on more traditional announcement of people's names.

My name comes up in lights so I know it's my turn.

We have a number when in the waiting area – I like the system.

They give me a card with a number. I sit down; when the buzzer goes it's my turn.

The nurse calls my name.

8.1.5 Physical access

Participants visited their doctors using a variety of travel modes: by walking, bus, private car or taxi, either independently or with a relative or paid carer. Some people had free transport as they had bus passes or taxi tokens while others had to pay full fare. Some people were dependent on the goodwill of families or paid carers to give them a lift and this often meant that they had to wait until it was convenient. As stated by one group, amongst whom two had asthma, two epilepsy and one a bad leg:

When you're not well, it can be very difficult to walk there.

In general, recently provided surgery buildings had good access. In addition, there was a view that surgeries were being modernised and improved, including with respect to access.

Practice being done up.

Updating small room.

Doctor's surgery is easier to access.

Ours is being modernised.

There's a ramp.

The surgery has an automatic door.

8.1.6 Home visits

Participants who had doctors who did home visits very much appreciated this. In general, while wishing that it might be otherwise, they accepted that home visits were becoming less common. There was also some criticism of the length of time between calling the surgery and a doctor visiting the home.

My doctor will do home visits when needed.

If you were in a wheelchair it might be good to have a home visit.

When I was severely ill I had to get the doctor out.

I walk to the surgery and hospital. If I'm too under the weather I will ring the surgery to come and see me at my house.

Call out is a long wait - can be from phoning at 9 am to 4 pm when they arrive.

8.2 **Communication Issues**

8.2.1 Patient with learning disability as the focus for communication

Participants had different preferences for how they wanted to consult the doctor. Some felt that they wanted to do this on their own. Others felt strongly that going with a supporter who knew them well, either a family member or familiar paid carer, was important and enhanced two-way communication. However, even when supporters were present, participants wanted to remain the focus of communication and in control of whether and when either their supporters spoke on their behalf to the doctor or the doctor directly addressed their supporters. This requires judgement by doctors about how to conduct a consultation with an individual as preferences vary not only from one person to another but also depend on the precise nature of the consultation. It also requires supporters to be disciplined in their role.

Some people are OK by themselves.

I would like to have someone to support me.

Important to have a support worker to accompany me, to help me communicate with the doctor.

I get very nervous if I have to speak to the doctor on my own. I like to have my support worker with me.

Important to have somebody with you – moral support and to help with what is being said.

They speak direct to me - that's the way I think it should be.

It's good when the doctor talks to you straight.

Doctor asks me what is wrong.

Sometimes only I know how I feel. It's my body not my mum's body. The doctor or nurse or receptionist needs to know that.

It is important that they look at you in the eyes and mouth. It is important to have a conversation, it is important that they ask you questions.

The doctor does listen to me. He makes it so I understand what he says.

The support worker comes in with me and talks for me, the doctor puts it on the computer. I speak more than the support and the doctor listens.

My mum talks to the doctor for me.

Sometimes the doctor talks to my support worker. I choose for this to happen.

Sometimes you need a support worker to help you remember good advice.

My doctor includes me and my mum when he explains things.

The doctor's the expert: my mum and dad go and help me to understand.

I have to tell my mum. Mum knows the right way to explain it.

My doctor speaks to my mum – I am happy with this.

8.2.2 Manner of interaction

How people were perceived to interact with them was very important to participants. They wanted to be taken seriously and dealt with politely as adults. Some participants reported that their doctors, nurses and receptionists had an excellent manner towards them. Others voiced criticisms.

I have lived in different areas and the surgeries here seem to be much more caring and supportive.

Everything is much better when people are nice to each other.

If you don't have good communication you lose all your confidence.

People at my surgery are polite - they speak to me.

Some staff are not respectful and I get scared.

Discussing doctors, they said

It's good when the doctor talks to us respectfully.

The doctors are friendly - they do make you welcome.

If you talk to the doctor nice, they will answer you in the same way.

They're good at talking to me. They know me and how to treat me

The doctors are calm and never shout. They go through my notes which makes me feel that they are showing me more attention.

Doctor should be interested in the person/patient.

When I tell the doctor I feel down in the dumps he just laughs at me.

Doctors can be very 'snobby'.

I would like to be treated politely and in a proper manner, and respectfully when I feel down in the dumps

Doctors and nurses do not always introduce themselves.

No eye contact. When he is talking to me he is more interested in the paperwork.

I started taking a carer to the doctors, didn't like the attitude the doctor was giving me. Get more respect if I have a carer.

My doctor is like talking to a stone wall: he only speaks and listens when I have my carer.

My doctor sometimes turns his back on me.

Sometimes the doctors are rude to me when I am alone and not rude if my care worker or mum comes with me.

Discussing nurses, they said

Very friendly and helpful. Explained things fully. Very efficient.

Always polite and respectful.

I see the nurse – it's good to know her name.

The nurse does more communication with me, she is more helpful sometimes – she knows what she is doing.

Nurses are generally helpful, sometimes they are not – can be naggy.

Discussing receptionists, they said

Some are very helpful.

Some are very polite.

I feel that they don't take us seriously.

Some are not good at communicating - they don't always seem to be listening.

She doesn't give me her full attention.

I don't like the receptionist.

Some receptionists turn a deaf ear to you.

Overall,

We would like staff to be polite, helpful, know what they're doing, smile and be welcoming, know us by name and say 'hello' with our name.

8.2.3 Time constraints and arrangements to make the consultation effective

Participants were very aware how busy doctors, nurses and receptionists could be. However, they also felt that having sufficient time when seeing the doctor or nurse was essential to having a satisfactory consultation. They appreciated it when surgeries made special arrangements to give them extended appointments. Some participants were clearly satisfied with the amount of time they were given. Others were not.

Not good at listening because they don't have time for you – always too busy.

Can be difficult to get personal attention – too busy.

The nurses are always busy.

Sometimes (receptionists are) very busy, doing too many things.

Important that people take time to listen to me.

Need time to be listened to.

We want time to be properly listened to and express ourselves.

It would be good to have a longer appointment to give us time to communicate better.

Appointment times should be longer for us.

My doctor gives me extra time if I need it.

Doctors can be bogged down, I have enough time with the doctor.

They (doctors) give me enough time.

The doctor gives me time to say what's wrong.

I feel I have enough time, she gives me good explanation that I understand.

I like the nurse, she gives me time. She listens to me and explains things to me.

The doctors are good at listening to me and take the necessary time.

They're good at talking to me. They know me and how to treat me.

Everybody listens to me.

Sometimes the doctor doesn't give me enough time and then explains things to my mum rather than me.

My doctor doesn't take time to speak. He doesn't understand me. This makes me feel awful.

8.2.4 Communicating clearly

Being able to speak to a doctor in the participant's preferred language is clearly important.

Participants discussed being able to speak Welsh rather than English and, in general, were satisfied, including in those areas of Wales where Welsh is most spoken. (There was no mention of other potential first languages.)

It's not a problem with Welsh in this area, although not all doctors speak Welsh. It's OK if we can choose who to see.

Some participants praised their doctors for giving straightforward clear explanations. In the third example below, one person indicated the importance of having the side effects of his new medication explained to him in terms of the action he then took to adjust his lifestyle to counter weight gain.

I understand the doctor, I have a proper understanding of what he says. He says it in proper English rather than medical terms. I feel I could stop and ask him what he meant.

I'm very happy with the way the doctor communicates with me. All the staff are very good with me. I have no complaints (I have 10 things wrong with me). They explained my medication very well to me.

It was explained to me that the tablets increased appetite for food. Because of this I go to a multi gym once a week and do aqua gym once a week.

Other participants said that they did not get enough explanation or that they did not always understand what the doctor or nurse said. They thought that more could be done to avoid jargon and to speak in simple language. A number felt that pharmacists talked to them better than their doctors.

They didn't tell me what was going to happen.

I don't understand everything that might be wrong with me. It would be good to have a better explanation.

Doctor just tells you to lose weight and doesn't tell you how. Need to explain things clearly.

Sometimes I have to ask my care worker to explain when I get home – the doctor should explain.

Don't explain what they are doing or why they are writing the prescription.

The doctor doesn't tell me what my tablets are for or how long to take them – he thinks I am twp (Welsh for 'simple').

Medication/tablets: it is not always explained what they are, what they do and if there are going to be any side effects.

The doctor doesn't always explain the effects of tablets.

Doctors don't always explain why they are changing medication, and don't always ask how it affects my lifestyle, especially for those of us who have epilepsy.

They need to tell you the results of tests (even if there is nothing wrong).

I like to know the results of tests rather than hear nothing.

Doctors do not always understand what the person is saying and the person doesn't always understand information given - talking in riddles, too much jargon.

I feel as if I am on a different planet to doctors and nurses.

It would be good if doctors could find out how people like to be communicated with and keep a record.

Doctor uses big language, don't understand him.

Sometimes I can't understand what the doctor is saying. I'd like the doctor to explain more clearly.

They mustn't explain too quickly.

Stop using jargon.

I prefer my doctor to use simple words.

Pharmacists give better advice – they have time for you.

Chemist always tells me to call if I have problems with my tablets – my doctor never says this.

Chemist is more friendly than the doctors, they chat about general things.

Some participants recommended greater use of non-verbal and non-reading-based means of communication to aid understanding, such as signing, pictures and film (e.g., using the television monitors in waiting areas for showing information videos and for advertising the services obtainable through the practice). They recognised that people who could not read required help with written materials and thought more could be done to have user-accessible versions. They suggested that training for the primary care team in appreciating the consequences of having a learning disability might be helpful. Some participants were already involved in providing such training.

For some people picture boards to communicate would be useful.

Pictures would help.

Pictures aid communication.

Video/TV in waiting room could give information about surgery, services, clinics etc.

Some surgeries already have TV screens, these could be used in a better way for accessible information.

Screen in the surgery is just writing - it has information about the doctors on duty - if you don't read you must rely on other people to help you by reading it to you.

If you have a sight or reading problem it can be very difficult.

Some information OK. But not all the time. Easier if in bigger print, tape. Common signs and pictures that everyone understand.

It would be helpful to use pictures to explain which tablet to take and when.

I would like a communication aid. Pictures would help.

Doctor needs to use simple language or sign language, pictures, films.

Leaflets in surgery: need easy to read versions – include picture book.

Patient booklets should be available in every practice. They should have accessible versions with pictures etc., Braille, talking books etc. Even more important if you don't read.

Educate doctors/nurses and health authority about making information more accessible.

Maybe they need to go on a training course.

They don't know about people with LD.

The (doctors) haven't been trained (for LD).

(We could) talk to them. Set up a group in the Health Authority to make accessible information.

There are some groups – we have some members in this focus group – who are learning to become trainers who will train professionals about what we need, also training receptionists.

Some saw a role for supporters to be party to all explanations so that they could help individuals understand better afterwards. However, they also stressed that supporters needed to know people well and to limit their support role to what the person with learning disability wanted.

Doctors and nurses can help you and your families to understand how to deal with epilepsy, asthma etc. Families and support workers should have information.

If people need to sign, they should have a support worker with them.

The staff at my home help to explain things that my doctor says to me.

If a support worker is going to help you to speak up to the doctor they need to know you well.

Sometimes support workers are yacking too much and don't listen or help.

Some participants mentioned the particular challenge of understanding doctors with a strong accent different to their own.

Sometimes it's difficult to understand what staff say because they have a strong accent. It would be good to have someone else to talk to who could help us to understand.

Can be difficult to understand explanations if English/Welsh is not their (the doctor's) first language.

Foreign doctors can be difficult to understand – you need an interpreter.

8.2.5 Privacy

Participants expressed concerns about privacy. Sometimes they were asked questions which they felt were too personal by receptionists in public situations.

Everything I say to the doctor gets kept confidentially. Sometimes I am worried about the receptionist being confidential.

Sometimes they (the receptionists) are very busy and they can make a comment to you that you don't want (confidential things).

The receptionist is good at keeping personal issues private, but sometimes the reception area is too open and everybody can hear what is wrong with me.

I'd like the receptionist to be screened off so I could speak privately sometimes.

I would like some privacy talking to the receptionist.

It should be clear that you don't have to explain to the receptionist what's wrong.

I worry other people can hear me.

Sometimes the patients will stare at you when you're trying to talk to staff.

It's terrible when staff talk about private things in public. It would be better if we could talk first in a private room.

8.2.6 Being put at ease

Participants recognised that, for many, going to the doctor made them anxious and that anxiety made speaking and listening to the doctor more difficult. Anxiety was not helped by having to wait a long time to see the doctor and the significance of long waiting times discussed above should be understood in this light. Participants appreciated having developed a relationship with their doctors and other members of the primary care team which gave them confidence. They also appreciated and suggested a range of practical arrangements which might counter anxiety. Unfortunately, some participants reported bad experiences with hospital services gained through referral from the GP. Such experiences amongst those who mentioned them seemed to have affected the confidence that they felt in their GP.

I feel a tad nervous when I see the doctor.

Some people get very anxious and it can make problems like asthma get worse. People may prefer to have a close friend to support them when they go to see a doctor – even more than a support worker, or advocate or family member.

It can be difficult to speak up because we can feel nervous. I feel panicky because they don't explain and I don't know what they're going to do to me. They don't know how to explain to me. They need to know.

Working on relaxing before you go in – you might need a laughter clinic!

Some nice music may calm people down or relax.

Very nice – make you feel relaxed. They explain things to me.

I have a laugh at the doctors.

I like my doctor to chat about things generally first.

I like my doctor being behind the desk so that we're face to face.

I prefer to go straight into the doctor rather than see the nurse too.

The doctor in the hospital said to my mum, in front of me 'does she understand'. I won't go there again. I always go with my mum – she was furious. Mother went to see GP to complain. But I've had no further feedback about it.

I had a bad experience with a doctor in hospital who gave me an injection without talking to me. It was an emergency. He didn't even speak or explain. I'm now scared of having injections from the GP. It's not too bad now if the doctor or nurse explains.

8.3 **Being Healthy**

On the whole, participants found it easy to list healthy foods, types of beneficial exercise and lifestyle threats to health such as smoking, drinking excess alcohol and becoming overweight. Many said that they had gained this knowledge through health education classes at school and college and from programmes on television. Some also recognised that they had received health advice from their doctor or nurse at the surgery: this was sometimes in the context of a health

check or particular clinic but was usually a corollary to going to see the doctor or nurse for a recognised health problem.

Being healthy is about your weight, exercise, eating the right foods.

Salad, low fat meals, fruit, skimmed milk, no beer!

Being active – not just watching TV.

Doctor has told me about healthy food and exercise, sometimes I do this. Didn't tell me why it was important.

Doctor has suggested I stop smoking – don't want to give up, my choice.

The doctor told me to do a lot of exercise and to keep walking.

I discuss with my doctor what I eat.

Participants recognised that their ability to respond to written health information was limited by their ability to read.

When purchasing foods: the food facts are too small. What's in them?

In doctor's surgeries: we can't always read the information about health awareness.

Some participants reported how they initiated courses of action for themselves.

I was conscious about my weight, so I worked out my own exercise plan.

I take cod liver oil tablets (I decided this myself). I get them from the chemist or supermarket.

People First groups had initiated holding 'Health and Wellbeing' days that offered general awareness raising on exercise, healthy eating and wellbeing. These days were sometimes a growth point for self-help groups. They had also provided accessible leaflets on these topics and on the use of leisure facilities. (NB They were also campaigning for the education of leisure centre staff to provide people with learning disabilities equal rights of access to realistically achievable activities).

However, it was clear across the focus groups that generally there was a gap between having knowledge about something and having the will or capability to act on it. This was evident, for example, in the case of people who had been recommended by their GP to lose weight and were willing to change their diet and exercise regime but lacked a suitable structured support programme to help them do this. People had tried generic programmes, such as WeightWatchers, but had quickly dropped out of them. No-one reported having access to programmes specifically adapted for people with learning disabilities. Some participants suggested that self-help/mutual support groups would be useful. There was discussion about where they should be based. It was felt that they did not necessarily need to be organised at or by the surgery.

If you want to lose weight and nobody helps you what do you do?

Staff in the house have takeaways and it's not helping me is it?

We need friends/carers to help us exercise.

If there was a healthy eating group in my surgery I would go.

Self help groups can be helpful – sharing experiences.

Meeting with like minded people to discuss health issues in a group.

Participants were confused about what they might expect from primary care in terms of practical health promotion. This partly arose from the fact that what surgeries offered varied and partly from a lack of knowledge of what services were offered by their own surgery. In addition, some services were difficult to obtain.

I don't know what happens in my surgery.

To see a dietician is nearly a year's wait.

Surgeries should have counselling services to help us stay mentally healthy.

We would like information about contraception or family planning.

Have information about herbs in doctors surgeries and alternative forms of medicine.

Good if the doctor could talk about alternative medicine or herbal medicine.

Some participants reported being helped by their GPs to access free exercise facilities, such as local leisure centres, either through direct prescription or by helping individuals obtain an access to fitness card. However, experiences varied. People suggested that it would be a good idea for local opportunities to engage in healthy activities to be advertised in the waiting room at the surgery.

Cards for leisure centre access are good, been to the gym, enjoyed it.

Exercise on prescription for some heart conditions is good.

I joined a gym but an access to fitness card is difficult to get sometimes. My GP wrote a letter – leisure centre wouldn't accept it.

Our surgery doesn't have a link with sports/fitness providers which we would like.

Some participants received regular health checks but the majority did not. Participants generally thought that having regular appointments for health checks initiated by the surgery was a good idea. Some people received an opportunistic health check when they contacted their doctor for another reason.

Surgery sends a letter every year to remind me to have a health check – I'm very pleased. I see the nurse.

Regular checks help people to get to know doctors and nurses well.

I would like this (to be invited for a health check). I have to contact the doctor.

We've just started going to the doctor for regular MOTs.

I hope to start health checks soon.

The doctor checks my blood every 6 months – unsure what for – blood pressure.

I go once a year for a check up.

I get a whole body check when going in with one problem.

They give me a good check when I go.

Commentary

Within each of the themes, participants had many positive experiences and much good practice to report. Some people with learning disabilities found it relatively easy to get appointments and reported good relationships with their local surgery staff. Some surgeries made special arrangements including giving people extended appointments and appointments at personally convenient times and at times which would avoid waiting. Some surgeries were also arranging regular health checks or checking health opportunistically when people attended the surgery for other reasons. Individual preferences about the conduct of consultations varied and some participants clearly felt that they had satisfactory control over them. Moreover, some doctors and nurses were regarded as reassuring, thoughtful and respectful of individuals' wishes and as providing good explanations of illnesses and treatments. Many participants had relevant information about healthy lifestyles and this was reinforced by information given at the surgery and awareness raising in self-advocacy groups.

However, the key issue in health promotion was how to adjust and maintain diet and exercise regimes and, for some, give up smoking. Participants reported an absence of effective practical support tailored to their needs. In this and in many of the other issues raised, people with learning disabilities may be similar to the general population. For example, it is likely that a proportion of patients without learning disabilities may consider difficult the process of ringing the surgery and negotiating an appointment at a convenient time. Most would find lengthy waiting times exasperating and tedious. Visiting the doctor can be anxiety-provoking to people without learning disabilities, particularly if the patient is uncertain how to explain their symptoms within a short consultation and their experience is that they do not see the same doctor every time. Understanding and remembering what the doctor says under the pressure of the consultation are well known to be common problems. However, a key distinction to be made is that the significance of such problems may be greater for people with learning disabilities. Critically, such people are likely not to have the confidence and persistence typical of other patients. Therefore, they are greatly

disadvantaged in social situations which call for a complex understanding and use of language and technology. It is, therefore, more incumbent on primary care professionals to adjust the typical appointments and consultation experience to suit people with learning disabilities.

It is important to appreciate that the participants in the focus groups are more articulate, confident and socially skilled than people with learning disabilities in general. It is likely that some of the difficulties that they reported facing will be greater for people with more severe learning disabilities. For example, being prepared for what will happen in examinations or being included in conversations to the extent of one's abilities may be more difficult to achieve. However, on the other hand, certain other issues may be less problematic for people with more severe learning disabilities than for people who in many situations can manage independently. For example, a person who usually makes telephone calls to friends successfully will feel deskilled if managing the process of making a doctor's appointment by phone proves too difficult. This will not be problematic for a person who does not ordinarily make telephone calls because of their limited spoken language.

While greater independence brings with it the challenges of exercising greater autonomy and responsibility with respect to making appointments, keeping and conducting consultations, understanding and following treatments and deciding upon and adopting lifestyle change, people with more severe learning disabilities than those attending the focus groups would be much more dependent on relatives and paid carers and have much less counter control should such carers, together with the primary care team, overlook signs of ill health or recommendations for healthy living. People with more severe learning disabilities are likely to be more reliant on their relatives or carers than the focus group respondents for sensitive support to identify and describe their symptoms, to understand the doctor's or nurse's explanations and to implement treatment or lifestyle changes. In the light of evidence that carers are sometimes not aware when the cared for person is ill, the primary care team should have an even more pro-active role than for people who are quite able to describe their own symptoms. This orientation should also be informed by the likelihood of physical and neurological morbidity being higher among people with more severe learning disabilities and the fact that some of the conditions which give rise to severe learning disabilities are also associated with specific ill-health, that is a physical phenotype. It is this pro-active orientation that provides the strongest rationale for health checking. It is interesting that the focus group respondents broadly supported the idea of

health checks, particularly the initiative that the surgery took to arrange and invite them to the appointment and the reassurance obtained from a practitioner giving them a thorough examination whom they recognised as more skilled than they were at spotting the signs of ill health. One could argue that health checking would be even more relevant for people with more severe learning disabilities.

Section 9: Reanalysis of the Mencap Cymru Database

The Mencap Cymru database was established as part of Mencap Cymru's contribution to the Treat Me Right campaign. It includes information on 178 adults with learning disabilities living in 18 of the 22 local authorities in Wales. Nearly half (46%) lived with their families, 29% in a shared house, 21% on their own and 4% in another type of setting. As well as eliciting such demographic information, the questionnaire asked respondents about:

- whether they had a health check in the last year or visited the doctor for another reason,
- how they thought that the visit went,
- whether they understood what was said,
- whether they felt that they had enough time,
- who went with them,
- whether information was directed at them or the person accompanying them and whether it was understandable,
- whether medication was prescribed and the purpose of the medication understood,
- how well the receptionist, nurse and doctor responded (on a scale from not good to excellent), and
- what could have been done to make the visit better.

Each primary question in the questionnaire was either factual (e.g., eliciting type of residence), designed to elicit a yes/no/not applicable answer or a subjective rating using a Likert type scale. After each, respondents had the opportunity to add comments. It is important to note that the wording of some of the comments in every section makes it clear that the comment was written by a carer. Moreover, it is not always possible to be certain in relation to other comments whether they were made by a person with learning disability or their carer. Nor is it possible to tell the contribution of people with learning disabilities or their carers to the answers given to the factual or yes/no/not applicable questions or subjective ratings. Therefore, the results need to be treated with some caution.

Findings

58% of respondents (n=104) said that they had a health check in the last 12 months and 70% (n=125) said that they had been to the doctors for another reason. Only 24 of those reporting to have had a health check said that they were invited by the surgery to have a check; the

remainder saying that they had asked for it. Therefore, it is possible that the term 'health check' was interpreted quite broadly as any visit to the doctor during which their health was investigated.

145 people rated how well they thought the visit went, with 60% saying it went well, 35% rating the visit as 'fair' and 5% rating it as 'bad'. Positive comments concerned how well people knew the doctor, being able to see a female doctor and having a doctor who was understanding, treated the patient well and explained matters clearly. Negative comments concerned being anxious, having to wait, not being able to go alone because the doctor wanted a carer to be present, and a difficulty with a receptionist in getting an appointment.

123 out of 146 people (84%) for whom the question was applicable said that they understood what was said at the doctors. Positive comments concerned the helpfulness and kindness of staff and the clarity of explanation. Negative comments concerned the doctor not speaking to the person with learning disabilities, not taking the time to explain, being difficult to understand or, through being foreign, not speaking good English.

131 out of 146 people (90%) for whom the question was applicable said that they felt that they were given enough time at the doctors. Positive comments concerned a general impression that individuals were usually or always given enough time. Negative comments reflected a feeling of being rushed.

32 out of 146 people (22%) saw the doctor alone, 59 (40%) went with a carer or supporter and 55 (38%) a family member. Comments mainly gave more detail about the accompanying person. A few comments stated that the person would rather have gone by him or herself.

60% of the people reporting that they were given information while at the doctors stated that it was given directly to them while 40% stated it was given to a carer, supporter or family member. 80% reported being given medication, with 87% of them stating that they understood what it was for. Additional comments were divided about two to one between stating that the doctor had explained the purpose of the medication well enough at the time and that either the patient did not know what the medication was for or that they had had to be told afterwards by a carer or family member.

134 (93%) had rated the receptionist's response to their visit 'excellent' or 'good', with the remainder rating it at 'not good' or 'ok'. The balance of comments was reasonably consistent with this, although some people stated that some receptionists were better than others and a few were critical of their abruptness.

114 people rated the response of a nurse to their visit and all rated it as 'excellent' or 'good'. There was only one negative comment made.

143 people rated the response of a doctor to their visit and 131 (92%) rated it as 'excellent' or 'good', with the remaining 12 (8%) rating it as 'not good'. Positive comments reflected feelings of having a good or long-standing relationship with their doctor and that the doctor was understanding. Criticisms concerned the doctor not taking the time to listen or talk to the person, being difficult to understand or being a different doctor every time.

When asked for suggestions to improve the experience of visiting the surgery, a considerable proportion of respondents stated that the existing service was fine. Suggestions from other respondents included shortening the time during which one had to wait at the surgery, improving diversionary activities while waiting, being able to see the doctor with an accompanying community or practice nurse, having more time with the doctor, having the doctor speak more clearly or take more time to explain and to be able to see the same doctor every visit. One person suggested that having an annual health check would be a good idea and two suggested the need for more practical help, one to lose weight and get fit and the other to stop smoking.

Commentary

The survey gives a positive general impression of primary care. Overall, the impression is perhaps of more satisfaction than was conveyed by the focus group findings. This difference may in part be attributable to differences in methodology. The primary questions in the Mencap Cymru tended to elicit a general indication of satisfaction with the service received. It is well known that satisfaction ratings tend to be skewed towards positive assessments. In addition, the findings reflect the views of carers as well as people with learning disabilities and it is also well known that the correlation between subjective self-reports and proxy-reports is low. Moreover, it is also possible that the focus group method encouraged a relatively greater airing of problems. Perhaps, the finding that stands out most in the comparison of the two sets of results is the agreement on the nature of the problems experienced: having to wait, being or becoming anxious, not having the autonomy to consult the doctor in the way one prefers, difficulties with the receptionist, communication problems with the doctor and difficulties arising from too short a time for adequate consultation.

Section 10: Primary care team views about the presence of health inequalities among people with learning disabilities and potential solutions to them

A questionnaire was sent to 24 general practices which participated in the PEARL research to elicit the extent to which primary care team members acknowledged the existence of various health inequalities among people with learning disabilities suggested by the literature, what they thought the reasons for this were and what they felt were the solutions to them, if any. The questions are listed in the box on the following page.

Questionnaires were returned by 11 practices. Telephone follow-up was made to 22 practices (two could not be contacted despite ringing several times) and additional comments were gained from two of them.

10.1 Obesity

10 practices responded that they recognised obesity was an issue of health inequality, the eleventh answered 'don't know'. Four practices identified problems in primary health care, including less frequent consultations, lack of access to or poor contact with health care, lack of access to health promotion and sub-optimal health education. Seven identified problems among people with learning disabilities, including immobility, lack of understanding, lack of motivation, communication difficulties, poor diet, lack of control over diet and a tendency for people with certain conditions to gain weight. Five identified other reasons, including carers permitting overeating out of misplaced kindness and lack of access to community activities which promote exercise. Solutions involving primary care included encouraging the general population to walk, use of the Patient Advice and Liaison Service scheme, greater time spent in explanation, giving advice on diet management, conducting health/weight checks and increasing awareness of health professionals. One respondent thought that provision of community nurse specialists would be a general solution to a range of health inequalities. Other solutions included education and support for families and carers, changing social attitudes and promoting access to structured or community activities involving exercise.

10.2 Sensory deficits

7 practices responded that they recognised sensory disabilities were issues of health inequality, two did not agree and two answered 'don't know'. Five practices identified problems in primary health care, including lack of facilities to check vision and hearing, infrequent assessment or lack of regular reviews, difficulties with communication and professionals being too accepting that the consequent limitations were due to learning disabilities (diagnostic overshadowing). Four

Questionnaire to General Practices

Part 1- General Medical Care

Q1 Research has suggested that people with a learning disability have higher rates of obesity as compared with the general population.

Do you agree with this statement? **Y** **N**

What issues do you feel underlie this?

- a. Within primary care
- b. In other settings

Do you feel there are any solutions to this? Please inform us of good practice you have found effective.

- a. Within primary care
- b. In other settings

Q2 Research suggests that people with a learning disability have high rates of unrecognised sensory deficits such as problems with vision or hearing.

Do you agree with this statement? **Y** **N**

What issues do you feel underlie this?

- a. Within primary care
- b. In other settings

Do you feel there are any solutions to this? Please inform us of good practice you have found effective.

- a. Within primary care
- b. In other settings

Q3 Research suggests that people with a learning disability have a low uptake of health promotion such as basic lifestyle advice, blood pressure and weight monitoring.

Do you agree with this statement? **Y** **N**

What issues do you feel underlie this?

- a. Within primary care
- b. In other settings

Do you feel there are any solutions to this? Please inform us of good practice you have found effective.

- a. Within primary care
- b. In other settings

Q4 Research suggests that women with a learning disability have low uptake of cervical cytology and mammography services.

Do you agree with this statement? **Y** **N**

What issues do you feel underlie this?

- a. Within primary care
- b. In other settings

Do you feel there are any solutions to this? Please inform us of good practice you have found effective.

- a. Within primary care
- b. In other settings

Part 2- Specific Complex Needs

Q5 It is recognised that people with a learning disability have high rates of mental illness, behaviour problems and the use of psychotropic medicine.

- a. Does this issue raise special challenges for the primary care team?
- b. How are these challenges met? Please inform us of good practice you have found effective.

Q6 It is recognised that people with a learning disability have high rates of epilepsy.

- a. Does this issue raise special challenges for the primary care team?
- b. How are these challenges met? Please inform us of good practice you have found effective.

Part 3 Solutions?

Q7 Special training in the health care of people with a learning disability is often suggested as a solution to the inequality of health care.

- a. What specific areas of training would make a change? Please inform us of good practice you have found effective.
- b. What difficulties may exist in getting this training?

Q8 Annual health checks performed, and funded, in primary care have been suggested as a solution to reduce inequality in health care.

- a. Do you feel this a feasible solution?
- b. What are the strengths and weaknesses of this approach?

identified problems among people with learning disabilities, including failure to complain and communication difficulties. Two identified other reasons, including carers in group homes assuming that problems are being dealt with and the need for good observation skills among day service and education staff. All respondents suggested solutions involving primary care. Most indicated some variant of better assessment or regular screening, involving liaison with optometrists and hearing specialists. Other solutions involved the general practitioner being more aware that there could be problems and giving time to and being more proactive about asking patients or carers about signs and symptoms. Solutions outside of primary care concerned optometrists visiting group homes to do home assessments and developing the skills of day service, education and group home staff to observe behaviour changes which might indicate sensory impairments.

10.3 Health promotion: Basic lifestyle advice, blood pressure and weight monitoring

8 practices responded that they recognised low uptake of such health promotion was an issue of health inequality, two disagreed and one answered 'don't know'. Six practices identified problems in primary health care, including difficulties in communication, shortage of time, health promotion being overshadowed by other problems and the stress of waiting at the surgery discouraging access. In addition, one respondent felt that primary care staff did not involve themselves in health promotion and relied on issues being dealt with by secondary care or other services. Three identified problems among people with learning disabilities, including level of learning disability and motivation, poor understanding, fear of examinations resulting in individuals not wanting to attend for appointments and an unwillingness to visit the doctor unless ill. Five identified other reasons, including social and media attitudes and carers lacking motivation or awareness, not understanding advice and not ensuring regular attendance at appointments. Nine practices suggested solutions involving primary care. Most advocated some variant of regular, proactive health checks either with the doctor or nurse individually or doctor and nurse together, better liaison with carers and improved consultation arrangements. The latter included more time, appropriate settings, convenient appointments to reduce waiting times and not attempting to do too much at a time. One respondent also suggested that carers should take a greater personal interest in the person with learning disability and be more responsible for ensuring that the person attended appointments.

10.4 Health promotion: Cervical cytology and mammography

10 practices responded that they recognised low uptake of such health promotion was an issue of health inequality, one answered 'don't know'. In general, problems were attributed to the

invasive or intimate nature of procedures causing anxiety or fear. Such problems were exacerbated by difficulties in helping patients understand the purpose of investigations and prepare for what was going to happen. In addition, assumed sexual inactivity made led respondents to think that cervical cytology was less necessary and would be more upsetting. Difficulties surrounding obtaining informed consent were emphasised, as were the need for conducive venue arrangements. Respondents were explicit that there were no easy solutions. Giving extra time and user-friendly appointments, taking pains to explain, carers attending as chaperones, involving carers in advance preparation and increasing practitioner training in health promotion were put forward as good practice. In addition, one respondent suggested that health promotion rooms might be established in schools and day centres with a visiting doctor or nurse.

10.5 Specific complex needs: Mental illness, challenging behaviour, psychotropic medication and epilepsy

A number of respondents felt that these specific needs did not cause greater challenges to the general practitioner because either their patients with such conditions were all under consultant care or they took the view that dealing with these issues was part of mainstream primary care. Other respondents felt that these needs did pose greater challenges: reasons cited were monitoring compliance with medication and its side effects, monitoring mental health, achieving satisfactory communication with the patient, the difficulty of prioritising (i.e., deciding which issue was the major management problem), increased workload, interaction with the severity of learning disability, ambiguity of treatment focus between patient and carer and lack of psychological services. Specifically in relation to epilepsy, monitoring medication was described as potentially problematic, especially if drug levels have to be measured. Venepuncture was considered to be stressful for the patient and practitioner alike. Being aware of possible drug interactions in relation to anti-epilepsy drug polytherapy was also considered a challenge.

The following arrangements were suggested as contributing to good practice: regular review, extended appointments, good liaison with carers, access to specialist advice from consultants and specialist community nurses, and checking physical health and sensory systems for possible causes for changes in behaviour. One respondent recognised that drugs were not always the answer and that behavioural programmes could be helpful provided that they were properly taught to carers. In relation to epilepsy, one respondent stated that monotherapy was good practice if possible. Two mentioned patients attending a specialist epilepsy clinic, at least one of which was held at the surgery.

10.6 Opinions about training and health checking as possible solutions

Some respondents identified types of training they thought had been or would be helpful. These included training on increased awareness of research, effective communication with people with learning disabilities and how to conduct an effective interview with a person with a learning disability, effective teaching methods, counselling skills and understanding syndromes. Obstacles to arranging or receiving such training in practice were overwhelmingly an absence of time, a feeling of being overburdened, the financial implications and the fact that receipt of such training was not in practice a quality indicator.

The majority of respondents supported the idea of annual health checking, albeit that one thought them unproven. Two respondents did not support the idea and one was undecided. Supporters felt the main strengths of health checks were that they would: ensure health monitoring occurred, not be dependent on patient request, result in a better service being provided without prejudice, provide a comprehensive, formalised examination and possibly result in picking up unidentified morbidity. One respondent felt that health checks were feasible in a group practice where it was possible to allocate health checking to a particular GP with interest in this area. Such an arrangement would also help training to be focused within the practice. The weaknesses of health checking were seen as the implications for GP time, practice resources and the need for training. Respondents also referred to the fact that one could not ensure that patients and where necessary their carers would attend and co-operate. One respondent who did not support the idea of health checks felt that they would result in resources going to people least in need.

Commentary

In many respects, the findings suggest that primary care teams have a realistic understanding of the complexities of achieving good health care for people with learning disabilities. Compared to the focus group and Mencap Cymru survey results, primary care teams more frequently attributed problems to the nature of learning disabilities, the behaviour of carers and difficulties in the wider community. Consistent with this, while respondents suggested solutions to health inequalities within primary care practice, they also pointed to the needs for staff training in other services, carer training, improvement in social attitudes and greater access for people with learning disabilities to community activities, particularly those involving exercise. Problems and solutions to problems within primary care echo issues raised in the focus groups: setting the occasion for more relaxed consultations (e.g., by reducing the stress of waiting), greater time given to assessment and explanation, more understandable advice, increased awareness of

potential health needs (avoiding diagnostic overshadowing), better assessment or regular screening, a more pro-active approach and better liaison with other specialists. Most supported introducing health checks.

It is important to re-emphasise though that the primary care teams sent questionnaires were those that had participated in the PEARL project. As such participation involved receipt of an educational package and pilot experience of health checking, it is possible that their awareness of inequality and their views about how to make primary care more effective may be atypical.

Section 11: Local Health Board views about the presence of health inequalities among people with learning disabilities and potential solutions to them

A questionnaire was sent to the 22 local health boards (LHB) in Wales to gain information about local measures to address health inequalities. In addition, a final question addressed measures being taken to meet the requirements of the Disability Discrimination Act. Following posting of the questionnaire, all local health boards were contacted by telephone to identify a named person who would be responsible for its completion. 12 completed questionnaires were returned. The questions are listed in the box on the following page.

Some respondents replied that there were no specific initiatives in the areas addressed by the questionnaire beyond the services ordinarily provided. Others referred to a variety of strategic goals and courses of action. A number of these referred to health checking. Two responses mentioned discussion within the strategic planning processes of the LHB concerning the feasibility of implementing health checking as an enhanced service. Another referred to the fact that the Welsh Assembly Government is also considering how to take this forward. Another referred to pilot implementation based on government funding received to implement recently issued guidance on learning disability services for adults. Two others referred to GPs in their areas conducting health checks.

One LHB reported that obesity had been adopted as a key target for the population as a whole and a number of others reported similar generic aims, coupled with initiatives such as the development of Healthy Living Centres, health passports and programmes such as Exercise for Life.

In terms of specific arrangements for people with learning disabilities, several respondents mentioned the role of community learning disability teams to monitor people's needs and make referrals for further assessments to be undertaken. One respondent mentioned that the teams in their area ran courses for people with learning disabilities on the theme of fun, fitness and exercise. One LHB also referred to a chronic disease team. Some local authorities and LHBs had put proposals forward for specialist nurse health facilitator posts as part of their plan to use funding made available by the Welsh Assembly Government alongside recently issued guidance. Several respondents referred to the Government requirement for all local areas to implement the Unified Assessment Process for adult users of health and social care services and that the annual review involved would provide another means to identify needs and plan to meet them.

Questionnaire to Local Health Boards

Part 1 - General Medical Care

Q1 Research has suggested that people with a learning disability have higher rates of obesity as compared with the general population.

Do you know of specific measures to address this in your area?

Q2 Research suggests that people with a learning disability have high rates of unrecognised sensory deficits such as problems with vision or hearing.

Do you know of specific measures to address this in your area?

Q3 Research suggests that people with a learning disability have a low uptake of health promotion such as basic lifestyle advice, blood pressure and weight monitoring.

Do you know of specific measures to address this in your area?

Q4 Research suggests that women with a learning disability have low uptake of cervical cytology and mammography services

Do you know of specific measures to address this in your area?

Part 2 - Specific Complex Needs

Q5 It is recognised that people with a learning disability have high rates of mental illness, behaviour problems and the use of psychotropic medicine

Do you know of specific measures to address this in your area?

Q6 It is recognised that people with a learning disability have high rates of epilepsy.

Do you know of specific measures to address this in your area?

Part 3 - Solutions?

Q7 Special training in the health care of people with a learning disability is often suggested as a solution to the inequality of health care.

Do you know of specific measures to address this in your area?

Q8 Annual health checks performed, and funded, in primary care have been suggested as a solution to reduce inequality in health care.

Do you know of specific measures to address this in your area?

Part 4 - Disability Discrimination Act

Q9 Do you know what measures have been introduced to meet the requirements of the Disability Discrimination Act in your area?

Other initiatives mentioned was one LHB leading local work on the interface between learning disability and mental health services. Another referred to Women's Health Education sessions organised at the day services in their area. One LHB also planned to hold a GP awareness raising day. Another referred to wanting to establish an Expert Patient Group for people with a learning disability and epilepsy but that this had yet to be agreed.

Not all questionnaires contained a response to the question about the Disability Discrimination Act (DDA). Those that did mentioned audits of health service estates (including primary care provision) for compliance with the DDA and the fact that the Welsh Assembly Government had ear-marked funding to meet the costs of building adaptation. A number also mentioned the

activities of departments within the local council responsible for equality issues. Apart from the audit of estates, measures undertaken included equality awareness training provided to all LHB staff, accessible versions of documents and provision, on application, of sign language interpreters for GP or dental consultations.

Commentary

The overall impression given is that addressing health inequalities among people with learning disabilities is an agenda to which boards have either just begun to respond or are in the process of planning to respond.

Section 12: Conclusion

Section 1 provides a descriptive review of the literature relating to health disparity among people with learning disabilities. Subsequent sections dealing with the PEARL research demonstrate a high frequency of certain morbidities associated with learning disabilities, an increased prevalence of obesity compared to the general population, a lower occurrence of some other lifestyle threats to health, and a low level of health promotion activities particularly among people with more severe learning disabilities. The evaluation of the impact of health checks showed that there is a case for annual checks as an effective way of identifying previously unrecognised ill health. In addition, health checking not only sets the occasion for various health promotion activities directly but also appears to increase the extent of health promotion undertaken during other consultations.

Despite this, it cannot be assumed that practices will make the additional time and resources for health checking available, nor that patients will necessarily take up the opportunity to have their health checked if offered. Although people with learning disabilities see their doctors more frequently than patients in general, their consultation rates may still be low in the light of their health needs and in comparison with some other defined groups such as patients with diabetes. Particular attention is required to ensure that people have access to effective care across the ability spectrum commensurate with their needs.

The focus groups and particularly the Mencap Cymru survey suggest that there is much good practice in primary care in Wales. However, practice is inevitably varied and both consultations point to a variety of ways in which the experience of people with learning disabilities in going to the doctor could be improved. These include arrangements to support independence and self-determination, preferential treatment to avoid some of the common difficulties in seeing the doctor, establishing the conditions necessary to improve assessment and maximise two-way communication, ensuring that patients are put at their ease and are the focus of interaction, simple and well-mannered communication, accessible information and more practical help with how to follow treatment regimes and lifestyle advice tailored specifically for people with learning disabilities.

Such requirements are reflected in the suggestions for good practice made by primary care teams. However, in raising problems in other areas, they suggest that action on health inequality for people with learning disabilities is not only relevant to primary care. Greater awareness is required by other professionals and support for healthy living has to be improved much more generally, including among immediate carers and the wider community.

While being generally supportive of health checking as one way forward, they are sensitive to the time and resource implications of comprehensive implementation within their already pressurised working lives. In keeping with the perspective of Local Health Boards, whether central government will provide the funding to make health checking an enhanced service is seen as a critical issue.

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Appendix 1: Additional comments from supporters (relatives & paid carers)

Visiting the doctor's surgery

Very good, friendly, don't have to wait long mostly it's come in – we'll fit one in. Very helpful, will refer on to run tests etc. if and when needed.

Could there not be a private booth each time receptionist asks problem etc.? – would benefit all - it is a inclusive society.

First and last appointments.

In (name) surgery it is common to have to wait a long time to see the doctor even if you have an appointment. Can be waiting up to 2 hours

Often unable to see own doctor so I have to see anyone – often means they are unaware of medical history and have to explain from the start.

If doctors are called out I sometimes have to wait until the next day, this makes me angry.

Doctors coming out to visit is a good idea. Although sometimes people have to wait all day/night.

Contacted carer in home support network and sheltered care who contacted doctor straight away.

In (town), the out of hours service is poor. Have to phone (name of service) – based in (distant town) who advises over the phone if you explain symptoms. They are able to prescribe over the phone – but without seeing you it can be hard to diagnose accurately.

Hard to get doctor out of hours.

(Out of hours) doctor (service) rang for ages, needed a doctor afraid he was displaying early symptoms of what could have been meningitis.

Mother gave up and had to ring NHS Direct Line, very helpful.

When (name) needed to be checked out for epilepsy, the doctor sent him for the tests using a hospital car which waited and brought him home.

Also when (name) needed to visit Cardiff re wheelchairs I have used a hospital car.

(Name) is male but likes female doctors.

Living together as an example for people with learning disabilities doesn't always work as carers are talking too much and won't help you to make a doctors appointment when needed.

If support workers (who are vital to accessing all services for people with learning disabilities) were well paid and given status as deserved it would help ensure good continuity of care

Communication

When the keyworker (support worker/key family member) is not there, who really knows what the client needs? Are the doctors notes consistent? Do they actually note this person has a learning difficulty or is the condition they were in only noted i.e. jabs, chicken pox etc.?

It would be helpful for all receptionists and doctors to have extra training on how to communicate with people with learning disabilities to help them understand.

For elderly people with learning disabilities it can be worse. Doctors don't listen.

Doctors at some practices treat you with respect.

Doctors are generally good at listening and talking explaining about what is happening.

Appointment cards are very important, taking time to listen and examine. Having a GP near you is so much better, nurses can be helpful for blood tests, nurses seem to listen more.

It is helpful to have someone with you like a support worker as the doctor can tell someone you know (always important).

Sometimes having family with you can help - or project worker.

Sometimes there is somebody with you all time if needed, this is better.

Having a choice about doctors who you communicate with can be a really good thing. We all agree about having a choice with a certain doctor.

Also having a social worker if no one else is available can be a good thing.

Having a record of what has been wrong with the patient in a book which you take with you can be very helpful in the surgery.

To a certain extent we should all be in charge of our own health

Last week I had a problem with the GP in (town). Due to the lack of parking spaces I had to leave my client to report to the reception at the surgery on his own due to his appointment time. After I found a parking space I got to the surgery as soon as I could. When I arrived I found that my client had been to see the GP without me, he had received a prescription for the same medicine that he normally gets even though he wanted to see the doctor for another reason. I asked the receptionist if I could go back to see the GP so that I could help my client to explain

why he needed to see the GP. She spoke to the GP and I was able to go back with my client to see the doctor. The GP hadn't realised that my client wanted to see him for a different reason. I helped my client to explain and I also explained that it wasn't right what he had done. The GP apologised and re-examined my client and gave him another prescription. My client is unable to communicate well as he can be very hard to understand at times as his speech can be a little quiet and can't pronounce his words well.

Nurse's room is not private. They have one big room so hold 2 consultations at the same time – often without a screen between. They are always at least 3 / 4 nurses in the room too, so it is impossible to talk in confidence.

Mum went to the doctors with K and explained to doctor that K has a learning disability and asked for it to be put on her notes and asked doctor to explain thing to K.

Written medication instructions are often unclear.

It would be helpful if doctor used symbols/pictures to show what time to take medication.

Information not just in written form. All persons are not literate, have perfect eyesight, not able to actually understand leaflet. Leaflet does not always answer the questions.

Accessible information.

Providing health information – still not accessible.

Healthy living information from other sources – we worked with them to make information accessible.

GPs/nurses to be able to communicate with individuals by using Makaton/symbols/pictures etc.

Doctors and nurses should have a little more training regarding people with learning difficulties e.g. communication and understanding.

Any public service who produces literature should have a resource which enables user friendly leaflets/letters etc. to be produced – e.g. plain language, talking materials. Individuals who work with people with learning disabilities should have some specific communication training.

When thinking about information it is important to consider 'easy read' format, perhaps illustrated.

Communication resources i.e. people with signing/Makaton skills, easy read/user friendly literature would need to come from the surgery i.e. doctor/specialist – out-sourcing these would bring problems around financial resources, availability, time, familiarity etc.

The health record book - if doctor doesn't look at it or complete it correctly can cause more frustration and lose patient/doctor relationship. Doctors will state haven't time.

Range of treatment available

Doctors need to have a more holistic approach (other ideas) i.e. massage, counselling. They state that homeopathy does not work because they cannot prove it, but they cannot prove it because their knowledge of science isn't wide enough. Yet some modern day medicine came from plants in the first place. They seem to have forgot – there is always – cause (disease) and effect (cure). If disease is on earth so is cure but not always in the orthodox way. We do not understand enough so why do they close their eyes and ears?

Feel more confident in doctors who are open in their position

Look at the 'whole' of your lifestyle. We all need somebody who understands us as an 'individual'.

Alternative therapist should be available. We should all have a choice.

We found that clients with learning disabilities have little choice about complementary medicines and would like to know more.

A better choice should be given between an alternative therapist. Clients can't do this if they have to pay for their own treatment. Both choices would be welcome.

Being healthy

Have a healthy diet (less sugar)

Wanting to be educated about your diet and check weight.

Self help groups can be good to share and swap information.

Leaflets at the doctor surgery are very good. Doctors will tell you about exercise.

Friendships and relationships are very important.

Information could be brought together and a health group could be started.

It can be difficult for certain individuals to get to leisure centres i.e. transport, no staff support.

Not all leisure centres are accessible.

I think that there should be more information for people with learning difficulties to find out more about healthy eating. Clients are not informed very well about food. I feel that there should be more qualified people to provide the relevant information regarding healthy food/eating to clients.

Keywords: Health inequalities: Learning disabilities; Wales