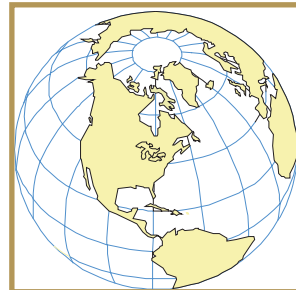
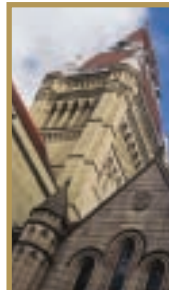


The role of health check programmes  
in improving access to mainstream  
NHS healthcare services for people  
with learning disabilities.

Alison Alborz  
November 2005



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## **Acknowledgements**

**Many thanks to Angela Swallow who conducted all practice interviews and Dave Hanson for conducting the audit of patient notes. The study was completed with funding from the Hester Adrian Research Centre Fund and the National Primary Care R&D Centre. This work was undertaken by the National Primary Care Research and Development Centre which receives funding from the Department of Health. The views expressed in the publication are those of the author and not necessarily those of the Department of Health.**



10 years

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executive summary 37

## The role of health check programmes in improving access to mainstream NHS healthcare services for people with learning disabilities.

### Background

People with learning disabilities are more prone to ill health than the general population. For example, it is well-established that people with Downs syndrome have increased risks of heart problems, hypothyroidism and early onset dementia (Howells, 1986). Their communication and cognitive difficulties mean that both they, and those who care for them experience difficulties in identifying signs and symptoms of ill health, hence approaches to healthcare services may be delayed. Health check programmes have been proposed as a means to facilitate healthcare to this group and several models have been trialled including nurse and GP led services. Previous published reports found that a high proportion of the health needs of people with learning difficulties were going unmet (Howells 1986; Wilson and Haire 1990; Harries 1991). However, few have investigated whether patients subsequently gained access to services.

### Aims

- To investigate the role of joint practice and learning disability nurse-led health checks in facilitating access to the full range of NHS services.
- To explore the experience of those implementing, running and using health checks in order to identify salient issues for service providers considering whether to offer this service.

### Methods

The study used a mixed methodology including audit and interview strands.

- Thirty-four sets of patient notes were audited on the 34 issues covered by health check protocols by the learning disability service for patients who had attended two or more health check appointments.
- The anonymised data on initial appointments was studied for evidence of follow up access to a range of healthcare services.
- In addition, a sub-group of 18 patients' second health check data was analysed to see whether the evidence supported offering regular as opposed to episodic health checks.
- Semi-structured interviews were conducted with practice staff at nine general practices and learning disability health professionals, who had experience of the programme.
- Six service users and their carers were also interviewed about their experiences.

## Results

### Initial Health Checks

- 97% of attendees had one or more health needs and 84% of this need received some follow up healthcare attention.
- In 76% of cases it was confirmed that the person had access to healthcare services in relation to identified need.
- In another 14% of cases there was strong evidence that healthcare services were accessed.
- Those needs that could be dealt with within the health check appointment itself were most likely to be met with 90% of preventative healthcare and 78% of health advice and education needs being addressed.
- 50% of patients were referred to a range of other healthcare services and access was confirmed for 88% of identified needs.

### Second Health Checks

- 78% of patients had one or more health concerns.
- Half of the group had fewer health needs noted at their second check, while 11% had the same number and 39% had a greater number of recorded health needs.
- 41% of the needs identified at initial health checks were no longer recorded as a concern.
- Persistent health concerns were evident, especially in relation to weight, blood pressure, diet and exercise.
- 84% of health needs noted in second health checks were recorded as having a follow up, as with initial health checks.
- In 73% of these cases healthcare services were confirmed as having been accessed in response to need. In a further 18% of cases, there was good evidence that services were accessed. These figures were very similar to the rates established for initial health checks (76% and 14% respectively).
- The need for preventative healthcare was most often identified. As with the first health checks, this was usually addressed within the health check appointment.
- Health education and advice where required was also given at the clinic.
- Referrals to other healthcare services were made for 39% of patients, compared to 50% who were referred on after initial health checks.
- 75% of identified needs requiring referral were addressed by the appropriate healthcare services.

### Health Checks Overall

- 24% (8) of the patients whose notes were audited in this study were diagnosed with a significant health problem, including hypertension, epilepsy and mental illness.
- Four were diagnosed as a result of a need identified at their first health check, two after a second health check and two after having a third health check. This suggested that regular health checks were needed if health problems were to be diagnosed and treated.
- The need for regular health checks may lie in the cumulative nature of addressing health issues provided by this type of programme.
- Patients with learning disabilities may not have every health issue checked at every health check and it may take time for the patient to feel comfortable with the nurses involved and with the setting itself.

- They may need preparatory familiarisation before procedures such as blood pressure testing can be undertaken.
- Patients who are extremely anxious may only be comfortable with very general questions about their health status initially. As familiarity builds, further health issues may be broached.
- There may be insufficient time to cover all areas of the health check.

### **The Interview Study**

- Practices wanted to ensure that their patients with learning disabilities were not disadvantaged in relation to their other patients.
- They also saw the involvement of the Joint Learning Disability Team (JLDT) as a way to facilitate provision of a 'well-person' check.
- Several practice staff had not previously thought of people with learning disabilities as 'a group' who needed special attention.
- The creation of a 'register' of patients with learning disabilities was seen by some as the first step to enhancing this awareness.

### **The Proportion of Patients in Practices**

- The numbers of people with learning disabilities in practices varied between 10 and 40 depending on practice size (between 0.001% and 0.007% of list size approx).
- The largest practices (>10,000 patients) reported having lower proportions of patients with learning disabilities (0.001% to 0.003%).
- The smallest practice (list size 2,000 approx) reported the largest proportion of patients with learning disabilities (2%).

The reason for this discrepancy was unclear. It may be attributable to the presence of a group home for people with learning disabilities in the catchment area. Where this is the case, people with learning disabilities may represent a larger proportion of the list size for small practices than the average.

### **Health Checks**

Nurses and carers saw health checks as appropriate for people with all levels of learning disability.

- For people with mild learning disability, who may have limited or no contact with services on a regular basis, health checks were seen as a useful link both to ensure that health appointments were being kept and to provide access to other services (specialist and mainstream).
- People with more severe learning disability have correspondingly greater health needs coupled with increased difficulties in recognising and communicating signs and symptoms of ill health. For these people, the health check was seen as a valuable opportunity to spend time investigating common health issues for people with learning disability in an ongoing way that built relationships and trust in their general practice.

## Annual or Biennial Repeat Clinics?

- Biennial clinics were perceived as more manageable logistically because they minimised demands on both practice and learning disability nurses.
- They were also seen as acceptable for people who were generally well or attending disease specific clinics at the same time.
- However, practice and learning disability nurses were concerned at leaving repeat surveillance for this long because of the underlying 'risk factors' (difficulties identifying need and seeking help).
- Carers also supported the provision of annual as opposed to biennial health checks.

## Resources

The resources demanded of practices and learning disability services varied. For practices, this involved a room and practice nurse time, which was estimated at between 12 and 15 hours over a number of months. This commitment was considered comparatively small and some managers felt the cost was easily absorbed by the practice. The resource commitment from the JLDT was significant because they were involved in clinics and meetings for the same number of hours as practice nurses, but also spent time distributing and following up appointments with telephone calls to clarify for patients what the check was for. This commitment was then multiplied by the number of practices running health checks. However, the JLDT service management regarded the resource expenditure as necessary because of obligations under the white paper Valuing People: A New Strategy for Learning Disability for the 21st Century (published on 20 March 2001)<sup>1</sup>, in regard to facilitating access to healthcare and providing health action plans. It was provided by prioritising health checks over other services.

## The Future

- Practices were positive about continuing the programme.
- Most wanted the programme to continue to be delivered as a joint practice and learning disability service because each nurse was considered to bring different strengths to the clinic.
- However, other models were proposed including moving to generic well-person appointments after an initial practice/learning disability health check.
- In the absence of a directive or incentive for practices to implement health check clinics, roll out to other practices within the PCT was predicted to be slow and problematic.

## Conclusions and policy recommendations

### NHS services should be more proactive

The NHS Plan (2000)<sup>2</sup>, and learning disabilities strategy document Valuing People (2001)<sup>3</sup> outlined the aspiration that people with learning disabilities should use mainstream NHS services (with appropriate support). Access to services was recognised as a key issue in relation to timely and effective intervention. To this end, considerable effort has been expended in ensuring that waiting times for appointments with health professionals and for treatment are kept to a minimum. However, the needs of people with learning disabilities mean they demand a more proactive NHS service, if they are to gain access to services in a timely and efficient manner.

## Regular Health Checks are Beneficial

Health checks appeared to be an appropriate vehicle to facilitate access to healthcare. Health improvement is difficult to ascertain in the absence of rigorous longitudinal studies. However, access to healthcare is a useful surrogate if one accepts the premise that timely access to appropriate healthcare is essential to health improvement. The access to healthcare demonstrated in the audit suggests that this group of individuals were likely to experience health benefits in the long run. The study also suggested that offering health checks to all people with learning disabilities on a regular basis would bring significant health benefits. The marginally reduced, but repeated identification of health need and diagnosis of significant health conditions over a succession of health checks suggested a need for regular, rather than episodic (life event prompted) checks. The definition of 'regular' would need to be determined by available resources, but it should occur no less than once every two years.

## Clinics should be nurse-led

Previous research has shown GPs are unwilling to become involved in health check programmes themselves (e.g. Kerr et al, 1996). This study found comparatively few of the individuals required referral to their GP. The bulk of their need was for preventative healthcare, and/or health education and advice appropriately provided by nursing staff. This study therefore suggests that clinics should be nurse-led.

## Acknowledgements

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<sup>1</sup>[http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilitis/LearningDisabilityPublications/fs/en?CONTENT\\_ID=4032080&chk=w%2Bvo48](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilitis/LearningDisabilityPublications/fs/en?CONTENT_ID=4032080&chk=w%2Bvo48)

<sup>2</sup>[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/AnnualReports/DHAnnualReportsArticle/fs/en?CONTENT\\_ID=4064827&chk=3ReuSO](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/AnnualReports/DHAnnualReportsArticle/fs/en?CONTENT_ID=4064827&chk=3ReuSO)

<sup>3</sup>[http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilitis/LearningDisabilityPublications/fs/en?CONTENT\\_ID=4032080&chk=w%2Bvo48](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilitis/LearningDisabilityPublications/fs/en?CONTENT_ID=4032080&chk=w%2Bvo48)

Kerr, M., Dunstan, F., and Thapar, A. Attitudes of general practitioners to caring for people with learning disability. *British Journal of General Practice* 46(403), 92-94. 1996

# **1. Background**

## **1.1 Health need**

People with learning disabilities are more prone to a wide range of physical and mental health problems than the general population; their healthcare needs therefore tend to be both complex and ongoing. For example, it is well-established that people with Downs syndrome have increased risks of heart problems, hypothyroidism and early onset dementia (Howells, 1986). Particular challenges arise in responding to the health care needs of new cohorts of people with learning disabilities who for the first time are living into old age (Fryers 1993; Carter and Jancer 1983); in meeting the health needs of people with learning disabilities within ethnic minority (particularly South Asian) communities (Emerson and Hatton 1999; ONS 1996); and in identifying and responding to the health needs of people who have additional mental health, behavioural and/or communication difficulties. Moreover difficulties in identifying the health needs of people with learning disabilities (Kerr et al 2003) mean these are often unrecognised and untreated (Howells 1986; Wilson and Haire 1990; Harries 1991). Following the closure of long-stay hospitals, responsibility for the health care of people with learning disabilities lies with mainstream NHS primary care and hospital services. Studies comparing people with and without learning disabilities have suggested that consultation patterns with general practitioners are similar though health problems differ, but preventative assessments are less likely to be performed (Whitfield et al, 1996; Langan et al, 1994). Given higher levels of health problems, these studies imply that people with learning disabilities under-access their general practitioners.

## **1.2 Policy**

At the same time as changes have been implemented in social care for people with learning disabilities, in terms of 'ordinary' housing, healthcare services have been undergoing fundamental revision. The modernization of the NHS includes, among other objectives, improving access to first contact and continuing healthcare and reducing inequities in the use of mainstream health services by disadvantaged and socially excluded groups (DH 1997; DH 2000). Policies for people with learning disabilities (DH 2001) also aim to improve their use of mainstream NHS services (with support if necessary). Specifically they propose that general practices should compile a register of their patients with a learning disability, and have offered them an individual Health Action Plan by June 2005. A new role of 'Health Facilitator', largely filled by specialist learning disability nurses, has been developed in order to improve access to and use of mainstream NHS services by patients with learning disabilities.



More recently in a drive to ensure NHS services are 'fair to all' (DH 2003), additional emphasis has been placed on services to adopt a person-centred focus, where equity is ensured through responsiveness to individual need. However, the legacy of development of separate specialised services, including health services, for people with learning disabilities in the past, is a mainstream health workforce unaccustomed to the interpersonal care needs of this group of patients.

Recent policy initiatives propose that people with learning disabilities should use mainstream services and this is fundamental to ensure they receive the 'state of the art' healthcare provided to the rest of the population. However thus far there has been less emphasis on the support and training mainstream health workers require to perform this unaccustomed role than the support people with learning disabilities need to access and use mainstream healthcare services. Should health checks be widely implemented general practices as a whole, and practice nurses in particular are likely to experience increased involvement in providing healthcare to people with learning disabilities.

### **1.3 Health checks**

Health check or screening programmes have been explored as a means to provide early detection and intervention for a range of conditions such as coronary heart disease. However many of these programmes have been found wanting, as the benefits derived have been small compared to the costs of providing the service (Wood, Kinmonth, Davies et al, 1994; Langham, Thorogood, Normand et al, 1996; Wonderling, Langham, Buxton et al, 1996). However, the particular needs of people with learning disabilities suggest that health checks may be of benefit to this patient group. The reasons for this are outlined below.

- Health checks for detection and early intervention for specific conditions have generally targeted the general population including significant numbers of people who are well and consequently do not require health services. People with learning disabilities, by contrast, are a small, relatively well defined group with known higher levels of health need who under-use primary healthcare. The health checks proposed for this group do not concentrate on specific health issues but span a range of risk factors and conditions that affect the general population but are over-represented amongst people with learning disabilities as a whole, particularly those with more severe learning disabilities. These include obesity, epilepsy, diabetes, mental illness, and sight and hearing problems, as well as syndrome specific health conditions such as thyroid dysfunction for people with Down's syndrome. The population in question,

therefore, arguably contains a greater incidence of health need to detect and chances of success are correspondingly increased.

- Unlike members of the general public, many adults with learning disabilities are heavily reliant on the familiarity of a close carer to recognise symptoms or indicators of abnormal health; to secure access to health care facilities; to interpret and communicate with health professionals; and support compliance with treatment regimes. Additional language and cultural barriers increase problems of access for people with learning disabilities from ethnic minority communities. In a recently completed literature review Alborz et al (2003) highlight the problems faced by carers, who often have difficult judgements to make about the appropriateness of seeking a health consultation. Faced with faulty or incomplete information and considerable practical difficulties in getting to and using mainstream primary healthcare facilities, it is not surprising that carers may not spot or misinterpret the significance of symptoms of ill health requiring professional attention. Identification of health need is in itself therefore an important goal for health check programmes.
- A number of studies that have established the effectiveness of health checks in identifying unmet health needs among people with learning disabilities (Martin et al, 1997; Barr et al 1999; Cumella & Martin, 2002; Cassidy et al, 2002), overcoming barriers raised by reliance on a purely reactive primary healthcare service. Studies have identified health problems needing attention in 72% to 94% of the people with learning disabilities being screened (Howells, 1986; Cumella & Martin, 2002; Cassidy et al, 2002). It has also been suggested that the demands of implementing such checks are acceptable to practice staff. For example, one pilot project found high levels of need among the 65 people who had health checks but that the initiative had a minimal impact on the workload of GP practice staff (Bollard 1999).

There is a lack of evidence, however, on the role of health check programmes in facilitating entry and continuing access to mainstream healthcare services. Martin (2003), in an investigation of annual health checks, found that referral rates to other healthcare services tailed off after two years, suggesting a 'front loading' of long-standing problems that had accumulated unrecognised for many years. This finding has implications for the utility of offering health checks in the longer term. A study on the effectiveness of health checks in improving access to mainstream primary healthcare services (Paxton & Taylor, 1998) suggested that accessing services was unproblematic and that service users and their carers

generally expressed satisfaction with services available. However not all referrals recommended were followed through. It has been suggested that access to sight and hearing tests, in particular may be limited by assumptions on the behalf of carers that such testing is not necessary (Wilson & Haire, 1990). These findings highlight the importance of carers to the performance of health checks aiming to improving access to healthcare. Impressive effectiveness in identification of health need, overcoming a primary obstacle to accessing healthcare, can be undermined if strategies are not put in place to facilitate subsequent action.

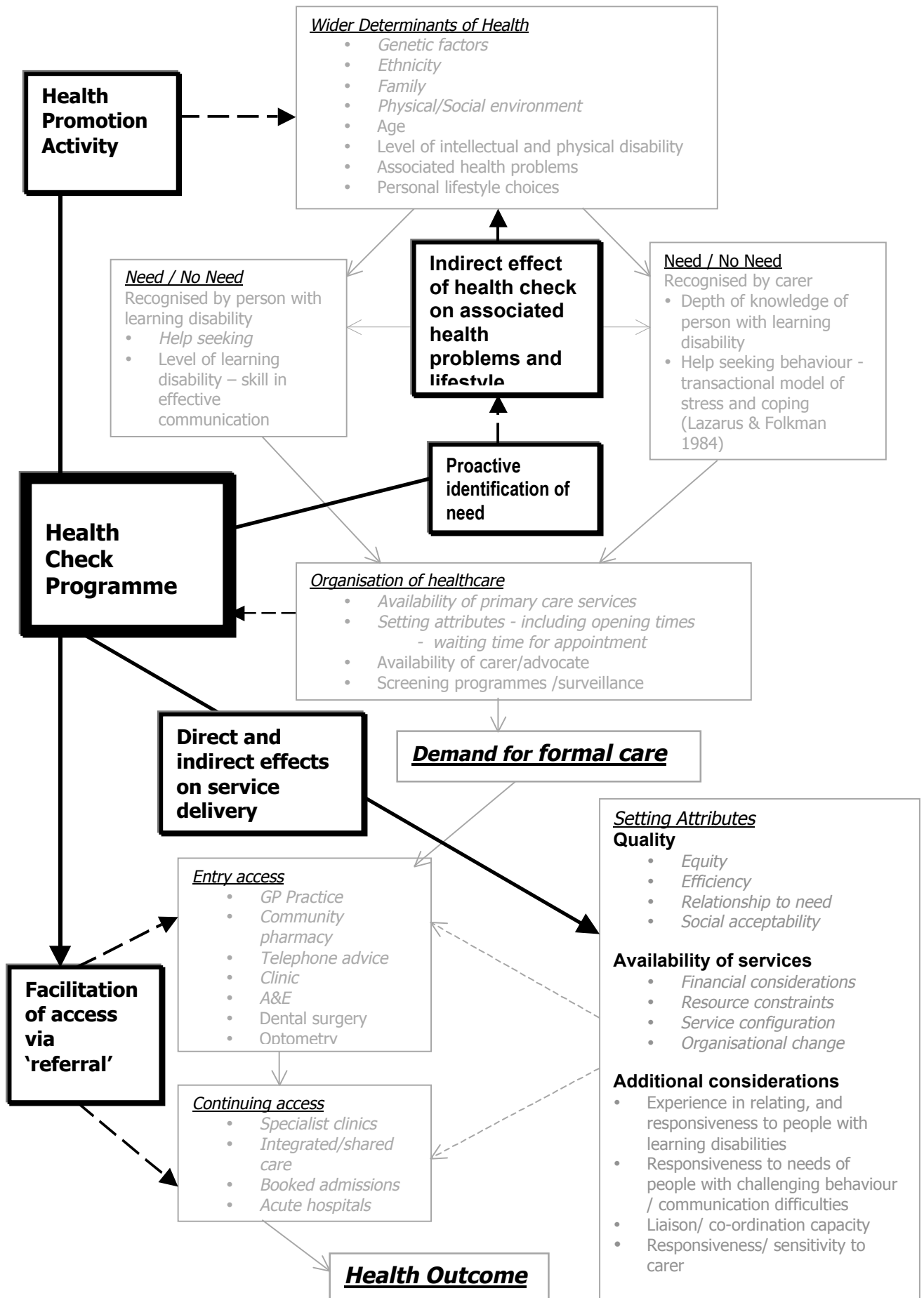
The implementation of health check programmes has the potential, therefore to impact on access to healthcare for this population in a number of direct and indirect ways. This is demonstrated in figure 1 overleaf, which builds on a model of access to healthcare for this group adopted in a recent literature review (Alborz et al 2005).

The recent consultative report 'Building on the best' (DH, 2003) suggests that health checks require further exploration and development before they can be offered annually to all people with learning disabilities. The possibility of health checks being adopted nationally within the NHS poses a number of questions about their role in improving access to healthcare services in the short and longer term. In particular evidence is needed on the impact of running a health check programme on general practice and learning disability services. This study aimed to address the issue of access to mainstream services and impact on general practice and learning disabilities services through investigation of a health check programme that had been in operation in a number of practices in one Primary Care Trust (PCT) for between two and seven years.

#### **1.4 The health check programme**

This wide-ranging health check led jointly by practice and learning disability nurses in general practice is repeated approximately biennially. The check addressed underlying conditions by screening for specific conditions, such as hypertension and diabetes. It provided preventative healthcare, such as tetanus vaccination or 'flu jabs'; and made referrals to mainstream and specialist health care services as necessary, including health promotion. It could not address the quality or effectiveness of any treatments subsequently received but nevertheless had the potential to impact on health status in the long term by facilitating access to initial and continuing health care.

**Figure 1: Impact of the Health Check programme on Access to Health Care for People with Learning Disabilities**



The programme aimed to:

- Help GP practices to compile a register of all their patients with learning disabilities;
- Overcome barriers to identifying and seeking help for a wide range of health needs among people with learning disabilities by providing treatment, preventive healthcare, and facilitating access to initial and continuing mainstream NHS services;
- Support people with learning disabilities in accessing primary and other health care services;
- Enable GP practice staff to become skilled in carrying out health checks and providing health care for people with learning disabilities;
- Embed regular health check programmes in the routine procedures of all general practices in the PCT;
- Support the implementation of the proposals in Valuing People (DH 2001) for improving the health care of people with learning disabilities by underpinning Health Action Planning.

The health check programme followed a standard format in each general practice which was repeated approximately every two years, including updating the practice register of patients with learning disability. The health check programme had been undertaken in a range of practices, including single-handed GPs and practices with high numbers of Asian patients where the implementation of the programme might be constrained by issues of capacity or acceptability.

This research therefore aimed to investigate the role of health check programmes in facilitating initial and monitoring on-going access to healthcare, and health action planning with people with different levels of learning disability and additional needs in a range of general practice settings. It aimed to explore the effect of health checks on paid and family carers' roles in identifying health need and facilitating access to mainstream healthcare services and its impact on practice and learning disability staff and services, including the extent of its integration into routine provision in participating practices and changes in its delivery over time. The study also aimed to explore the implications of roll out more widely across the PCT.

## **2. Methodology**

### **2.1 Design**

This study adopted a mixed methodology. Quantitative methods were used to analyse patient audit data on health checks while qualitative methods were used to explore the views and experiences of practice and learning disability nurses running health check clinics, as well as those of people with learning disabilities and/or their main carers. The qualitative study also explored the experience of the programme and potential for wider roll out across the PCT through interviews with practice staff and learning disability nurses and managers.

A member of the joint learning disability team conducted an audit of patient notes to provide anonymised data for analysis. Interviews were conducted by university researchers with practice managers and nurses, joint learning disability team nurses and managers, and service users and their carers.

Ethical approval was gained for the study from the local LREC and the University ethics committee. University researchers obtained CRB authorisation for contact with vulnerable adults. The project was also approved by the PCT research governance committee.

### **2.2 Instruments**

#### **2.2.1 Audit**

People who had experienced two or more checks were selected for audit so that we could be confident that sufficient time had elapsed since their initial health check for follow up to have occurred. It was reasoned that where referrals to other services are necessary these might take some time to complete, and information on access to services such as dentists or opticians might only be gained from carers at subsequent clinics.

An audit sheet was used to collate data on health checks from service records. One sheet was completed for each health check attended and recorded health issues checked, of concern and subsequent action. It also included brief information of existing health conditions (see Appendix 1). Anonymised information was then entered into an SPSS database for analysis.

### **2.2.2 Interview Study**

Topic guides were developed for the interviews which, given the nature of the study, directed the discussion to the issues of concern but allowed exploration of issues that emerged in response to the initiating question.

#### ***Healthcare professionals interviews.***

Structured descriptive information was collected on professional background and a topic guide was provided prompts for discussion (see Appendix 2). Practice interviews centred on:

- Awareness of patients with learning disabilities and issues prior to implementation of the health check programme.
- Reasons for implementing the programme and how the decision to proceed was taken.
- Apprehensions about running clinics.
- Experience and impact of clinics for practice staff.
- Perceived impact on patients, carers and other patients registered with the practice.
- The future of the programme within the practice.

For learning disabilities nurses the interviews focussed on:

- Experience of promoting and running health check clinics in a range of practices.
- Impact on individual's workload.
- The future of the programme.

In addition for learning disability service managers the interview included:

- Development of the programme within the service to date.
- Impact on the service overall.
- The future of the programme.

These interviews were transcribed and subsequently analysed using NUD\*IST 9 software.

#### ***Service users and carers***

##### ***Carers***

Background information on the person with learning disabilities living circumstances, disability and significant health concerns was collected using a structured questionnaire. Use of primary health care and experience of health checks was then discussed using a topic guide (see Appendix 3). Carers were invited to discuss:

- Use of primary health care services by the person they supported.

- The invitation to attend the health check and arrangements needed to enable them to attend.
- The health check process, including impact on the person they support and themselves.
- Future attendance.

Service user data was entered into an SPSS 11.0 database for summary and transcripts from interviews were analysed using NUD\*IST 9 software.

### ***People with learning disabilities***

A topic guide was used to explore the views and experience of people with learning disabilities (see Appendix 4). The interview was designed to first allow the interviewee to become comfortable with the interviewer by asking 'ice breaker' questions about home and working life. Use of healthcare was then explored and finally having a health check was discussed.

People with learning disabilities were asked a range of questions including:

- General questions about their daytime and home activities.
- About using primary health care
- About the health check process, including why they had a health check and the outcome.
- Whether they would attend another health check when invited.

Transcripts were analysed using NUD\*IST 9 software.

## **2.3 Participants**

The primary care trust (PCT) involved in the health check programme covered a total of 67 doctor's surgeries. Ten practices had implemented health checks for patients with learning disabilities over two to eight years by December 2004. Audit was conducted on patient notes for 34 people attending five different general practices. Nine practices, representing 12 doctor's surgeries, agreed to interview. One of the partnerships provided services to two surgeries and was a PMS practice. Another was run by the PCT itself and was one of four surgeries managed by the same practice manager. The remaining practices were all single site GMS practices. Practice list sizes varied between 1,987 and 19,017, with two practices having less than 4,000 registered patients, four practices having between 4,000 and 10,000 registered patients and two having more than 10,000. The list size is not known for one practice, however this was a single handed practice and therefore the number of registered patients was likely to be small.



### 2.3.1 Participants in audit of patient notes

The audit was conducted between December 2004 and January 2005 by a nurse from the Joint Learning Disabilities Team (JLDT) on 34 sets of patient data from five separate practices. Practice list sizes varied between 3462 and 19017 patients and included three practices with list sizes under 5000. Patient data included both demographic data (e.g. ethnicity, living arrangements, level of learning disability, additional health problems) and health check outcome data (as outlined above).

The sample comprised 24 men (71%) and 10 women with learning all of whom had received two or more health checks. The decision to select patients with more than one health check was made to ensure that sufficient time had elapsed between the initial health check and the audit to allow follow up 'access to healthcare services' to take place. 31 of the group were white British (91%) and 3 Asian. Their ages ranged between 22 and 72 years (mean 47.4, median 48.5). Sixteen people had attended two health checks (47%), 11 (32%) had received three health checks, and 7 (21%) had had four health checks. Age and severity of learning disability for the sample is shown in Table 1 below.

**Table 1            Age and severity of disability among people with learning disabilities**

		Level of learning disability			Total (%)
		Mild	Moderate	Severe /profound	
<b>Age Group (years)</b>	20-29	0	2	0	2 (6%)
	30-39	2	1	2	5 (15%)
	40-49	3	5	3	11 (32%)
	50-59	2	4	6	12 (35%)
	60-69	1	2	0	3 (9%)
	70+	1	0	0	1 (3%)
	<b>Total</b>	<b>9</b>	<b>14</b>	<b>11</b>	<b>34</b>

Twenty one percent of patients were under the age of 30 when they had their first health check, 58% were aged between 30 and 49, and the remaining 21% were aged 50 or older. A number of people suffered a range of additional or specific problems as listed below (Table 2).

**Table 2 Additional problems noted among audited sample**

<b>Additional Problem</b>	<b>No. (%)</b>
Visual impairment	2 (6%)
Hearing impairment	2 (6%)
Physical disabilities	7 (21%)
Autistic spectrum disorders	4 (12%)
Dementia	1 (3%)
Mental illness (Dual diagnosis)	8 (24%)
Challenging behaviour	4 (12%)
Complex health needs	7 (21%)

There was no relationship between gender or severity of learning disability and number of additional problems recorded. Table 3 shows the number of additional health problems for people with different levels of learning disability.

**Table 3 Additional health problems by level of disability**

		<b>Number of additional problems</b>				<b>Total</b>
		<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	
<b>Level of learning disability</b>	Mild	3	3	3	0	9 (26%)
	Moderate	4	4	5	1	14 (41%)
	Severe /profound	7	0	1	3	11 (32%)
<b>Total</b>		<b>14</b>	<b>7</b>	<b>9</b>	<b>4</b>	<b>34</b>

Six of the sample were also recorded as having Down's syndrome, two had Cerebral palsy, 1 person had spina bifida and one tuberous sclerosis. Three people were known to have

thyroid problems, including two of the people with Down’s syndrome. Four people suffered asthma, six were epileptic, and five had heart conditions. In addition, five people were diagnosed as suffering mental illness, two had hypertension and one hepatitis B. One person had a mobility problem and was incontinent.

Seventeen of these individuals resided with their family (50%), 13 (38%) lived in supported tenancies, two lived independently with outreach support (6%), and two lived independently with no support (6%). Table 4 describes living arrangements for people with different levels of learning disability.

**Table 4 Residence by level of learning disability.**

		Level of learning disability			Total (%)
		Mild	Moderate	Severe /profound	
<b>Living arrangements</b>	Family	3	8	6	17 (50%)
	Independent	4	0	0	4 (12%)
	Group/network home	2	6	5	13 (38%)
	Total	9	14	11	34

As expected only more able people with mild learning disabilities were living independently while those with more severe learning disabilities tended to live in group/network homes for people with learning disabilities. The latter included statutory, independently run and not-for-profit housing schemes. More than half the people with moderate and profound learning disabilities were living with their family compared to only one third of those with mild learning disabilities.

There was no statistical relationship between age and number of health checks received, number of additional health problems, severity of learning disability or residence. However, as anticipated a larger proportion of younger adults were living with their families. People with a greater number of additional health needs were more likely to be living in group/network housing than independently or with family ( $X^2(1)= 5.438, p=0.020$ ).

### **2.3.2 Participants in Interview Study**

### **Practice interviews**

Following introductory information about the study, circulated by the JLDT, a researcher contacted practices directly to obtain permission to interview and arrange appointments. Interviews with practice managers and nurses were conducted separately and in private on practice premises. In all but one of the nine practices that took part in the study, both the practice manager and a practice nurse involved in providing health checks were interviewed. In the latter practice the practice nurse alone was interviewed.

Practice managers (7 females, 1 male) had been in these rolls for between 3 and 15 years, and practice nurses (11 females) had been between 2 and 17 years experience. As Table 5 below shows, these participants comprised a highly experienced group of professionals.

Semi-structured interviews were held separately with practice managers and nurses and lasted between an hour and an hour and a half. One interview took 2 hours however this was completed over two separate appointments.

**Table 5 Professional profiles of practice interviewees**

	Practice managers (N=8)*	Practice nurses (N=11)
Experience in current role		
< 5 years	1	1
5-10 years	2	4
>10 years	4	6
Employed in current practice		
< 5 years	1	2
5-10 years	4	5
>10 years	2	4

(\* details missing for 1 practice manager)

Interviews were conducted in November and December 2004. This was a period of extensive change for practices as the conditions of the GMS contract were about to take effect. All the practices had been extremely busy summarising patient notes, updating computer systems (in particular applying Read Codes for specific medical, and appropriate social conditions) and devising their Quality Outcomes Framework aspirational targets ready for the first data

gathering exercise to be undertaken in early 2005. Most practices had run second or subsequent health check clinics for their patients with learning disabilities during 2004. This round of clinics followed a break in service due to changes in delivery of community nursing services for people with learning disability.

### ***Joint learning disability team interviews***

Following approval from the JLDT manager and briefing by a JLDT team leader, learning disability nurses were approached by a researcher to gain consent to interview and arrange appointments. Interviews were conducted separately and privately on JLDT premises.

The specialist learning disability health service joined social service colleagues in 2002 to establish a joint service for people with learning disabilities, lead by social services but with funding from the PCT. The administrative and accommodation changes for the learning disability nurses meant that for a brief time they were unable to support health checks in general practice.

Early health check clinics were supported by a number of different learning disability nurses, however, as the team settled into its new format one nurse was given the sole role of initiating and supporting health checks in general practice. Consequently recent clinics were supported by this learning disability nurse alone and only two other nurses currently employed by the team had prior experience of this initiative. The nurse with current responsibility for running the programme (female) had 32 years experience as a learning disability nurse and 4 years involvement with the current service. Another female nurse had experience of assisting in health check clinics in three general practices, while the male learning disability nurse had experience with only one practice. These nurses had 16 and 13 years experience, and had spent 1 and five years with the current team respectively (Table 6 overleaf).

**Table 6 Professional profiles of JLDT staff interviewed**

	JLDT nurses (N=3)	JLDT team leader/manager (N=2)
Experience as CNLD		
< 10 years	0	0
10-20 years	2	1
>20 years	1	1
Involved in running health checks		
< 2 years	1	0
2-5 years	2	0
>5 years	0	1

In addition to these learning disability nurses, the learning disability team leader (male) currently responsible for the operation of the programme, and the joint learning disability team manager (female) were interviewed in early 2005.

### ***Service Users and Carers***

To preserve anonymity in the first instance, approaches to carers and service users were made through the joint learning disability team leader responsible for the programme. He first telephoned and then sent out information packs about the project to 25 carers of people with learning disabilities who had attended health check clinics. The information pack contained full written details about the study for carers and a video letter for service users (who were considered capable of participating in interview by their carer). Consent forms and FREEPOST envelopes were included for both carers and service users to return to the investigator if they were willing to be interviewed. In all 6 service users and their carers (N=8) consented to be interviewed. This was a disappointing response rate. The reasons for this possibly relate to carers believing that the service user *must* take part. The information sent to carers included information about participation by carers alone as patient representatives where the person's communication skills did not allow interview, or with the person's consent if they did not feel confident about being interviewed personally but did not object to their carer speaking on their behalf. At the outset it was understood that not all people with learning disabilities could, or would want to, be interviewed but every effort was made to ensure that people able to express a view could provide informed consent. The information collected from the six households, however, is incorporated in the analysis as appropriate.

Six service users (3 male, 3 female) and their carers were interviewed about getting health care and experience of having health checks. Their ages ranged from 36 to 72 years with four people in their 40s. Carer interviews were conducted with one female adult placement carer, four female group home carers, one father and jointly with a mother and father. One man was living with his parents full-time and another lived partly with his father and partly in his own home. Two women and a man were living in group homes with 24 hour carer support and one person lived in private accommodation with an adult placement carer. Five people were fully mobile and one was mobile in a wheelchair. Two people were described as being able to use money and check change, three further people used money but could not check change, and the sixth knew money had value but could not use money. All households had use of a car for getting to appointments.

### ***Health status of participants with learning disabilities***

All service users were described as physically fit in relation to acute bouts of illness such as colds and flu. However they all had additional health problems, two people were registered blind and one had a significant hearing impairment. The person with mobility problems also had substantial physical problems (including being partially sighted) which meant he was more dependant on his carers than other participants in many respects, however his communication skills were better than most. One person suffered epileptic fits which had been present since childhood, four people had mental health problems including three suffering anxiety and/or depression and one who was schizophrenic. One person had suffered their condition since childhood, one had developed during adolescence and two others had been diagnosed in adulthood, but before they commenced health checks. None suffered diabetic or heart conditions, although one person had received treatment for fluid around his heart. Other significant health problems suffered by four of the six participants included hiatus hernia, phobias/panic attacks, iritis and arthritic flare-ups, sleep apnoea and cancer (currently clear), and thyroid problems. They all had good communication skills, though one person's hearing impairment and lack of dentures made his speech difficult to understand.

### ***Health service contacts***

Routine health contacts amongst the group comprised GP visits (3 people), medicine review with the psychiatrist (3 people), dental visits (5 people), sight tests (5 people), chiropody (2 people), audiology (2 people), and blood pressure monitoring (1 person). Three people also had occasional contact with the accident and emergency department but only one used A&E

on more than one occasion. This woman sometimes suffered injuries in the course of epileptic fits.

### ***Help seeking***

Four of the six people were described as having good help-seeking skills and their carers were confident that they would tell someone if they were not well. One person tended to take herself off to bed if she was unwell which alerted staff. If she was in physical pain (stomach, head or tooth ache) she would tell a member of staff. One person however avoided revealing he was unwell, partly, in the opinion of his carers, because he did not wish to miss day centre activities and partly because he has a hospital phobia and realises that sometimes illness results in hospital contacts. All carers indicated that they actively sought health advice on a regular basis apart from in two specific instances. One involved dental checks for a person who had no teeth. This person had lost his teeth many years previous to moving into his current residence two years earlier and as far as the carer could tell he had had no dental visits since that time. His dentures were broken and were not replaced. The second instance was where the person was blind and had no optical health checks of any kind.



## 3. Results

### 3.1 Patient Note Audit

#### 3.1.1 Initial health checks

JLDT nurses used a standard protocol for their contribution to the health check while practice nurses used their own practice 'well-person' protocols. The health audit therefore covered 31 issues in total that might be reviewed with any patient during their health check. An additional two items addressed breast and cervical screening for women with learning disabilities, one item addressed family carer needs and the last item checked occupation (see Appendix1). Although the audit was carried out on all these areas, not every area was mentioned in every patient's notes. However, failure to note that a health area was checked cannot be taken to mean that no check was made. In at least one case it was clear that notes were only made where an area was cause for concern. The impact of this on the study is explored in the discussion section below. These analyses are based on the 31 health areas potentially applicable to all patients with learning disability. However a brief analysis on data obtained on women's health issues covered is given below. The frequency of health issues/concerns recorded in initial checks over the 31 areas is listed below.

**Table 7 Health issues checked and noted as a concern during first health check  
(Continued on page 24)**

<b>Healthcare need in relation to:</b>	<b>Recorded as checked* N (%)</b>	<b>Concern noted * N (%)</b>
Family history	7 (21%)	1 (3%)
Medical history	8 (24%)	5 (15%)
Smoking	27 (79%)	1 (3%)
Alcohol consumption	28 (82%)	0
Weight	32 (94%)	16 (47%)
BMI	21 (62%)	10 (29%)
Blood pressure	26 (77%)	3 (9%)
Pulse	0	0
Urine test	20 (59%)	2 (6%)
Blood sample tested	6 (18%)	6 (18%)
Thyroid function test	2 (6%)	2 (6%)
Cholesterol level test	3 (9%)	3 (9%)
Immunisation history	15 (44%)	11 (32%)
Ears checked (wax)	3 (9%)	3 (9%)

**Table 7 Health issues checked and noted as a concern during first health check  
(Continued from page 23)**

Diet checked	24 (71%)	11 (32%)
Exercise level	27 (79%)	5 (15%)
Sleep pattern	1 (3%)	0
Skin	1 (3%)	1 (3%)
Feet	10 (29%)	2 (6%)
Allergies	4 (12%)	0
Contraception	5 (15%)	2 (6%)
Continence	17 (50%)	7 (21%)
Dental visit	17 (50%)	3 (9%)
Sight test	23 (68%)	13 (38%)
Hearing	17 (50%)	7 (21%)
Epilepsy status	18 (53%)	4 (12%)
Asthma	0	0
Mobility	7 (21%)	2 (6%)
Medicine review	15 (44%)	0
Feeding	4 (12%)	1 (3%)
Mental health / behaviour problems	13 (38%)	5 (15%)

(\* N=34 for family history to exercise; N=33 for sleep to mental health)

Thirty three people (97%) had one or more health needs identified in their first health check. Of the 116 health concerns identified, 97 (84%) were recorded as having some follow up action. The table below shows that weight (47%) was most often identified as an area of concern, followed by concerns about sight (38%), and concerns about diet or immunisation status (32% each). BMI was a concern for more than 1 in 4 people (29%) and hearing or continence was an issue for more than 1 in 5 (21% each).

In addition for women, health checks with 2 of the 7 women over 50 years of age had addressed breast screening however there were no concerns arising from the checks. Five of the women's health checks addressed cervical screening, and concern was noted for 3 women. The consultation also provided an opportunity to ascertain whether family carers' needs were being addressed. 7 of the 17 sets of notes (41%) relating to people with learning disabilities who resided with their family recorded a check on carer needs. There were concerns about the needs of 3 of these carers (9%). In all these cases, carers were noted as elderly. No further follow up action was available within audited notes because such notes would be found in carer's own notes which were not included in this audit. Finally the consultation was an opportunity to check that the person was receiving adequate day time

opportunities for work or other occupation. 15 sets of notes (44%) recorded enquiries regarding daytime occupation. Again there were concerns regarding access to services/occupation for 3 people (9%).

### **Access to services**

The major focus of this audit was to establish whether the health check facilitated access to healthcare, that is, having identified a need (or concern) were appropriate health services were accessed? This is a primary goal for health checks that aim ultimately to achieve an improved health status for this population. Patient notes were therefore checked for evidence of follow up of the identified need. The quality of evidence can be variable however, especially where notes are made by staff who are unaware of the need for later audit. For the purposes of this study, therefore, the evidence was rated as excellent, good, or poor, depending on how confident one could be that healthcare services had been accessed. For example, a letter from a consultant regarding a referral following identification of a particular need would be excellent evidence of access to services. A note of an appointment to see a particular health practitioner would be good evidence rather than excellent, because it provides information only that the event is scheduled to take place but not that it did in fact take place. A poor piece of evidence would be a tick against a concern that a person needed a tetanus injection for example, or note that a carer was advised to make an appointment. Table 8 overleaf lists the evidence of follow up in relation to need identified in initial health checks. Of the 116 health needs identified 97 (84%) were noted as receiving some follow up action.

Only 3 (9%) of the 34 individuals (all registered with different GP practices) were receiving a yearly influenza vaccination prior to attending health checks. By the time of the audit (December 2004) 20 people with learning disabilities (59%) were receiving yearly influenza vaccinations. Five people received their first injection during their first health check and 3 more between their first and second checks. A further 8 people began yearly influenza injections at their second health check. One person did not start to receive these injections until between their third and fourth health checks, which coincided with the onset of heart problems.

The type of follow up action taken in response to identified need fell into five categories.

- *Preventative actions* included vaccination against health risk, or screening or monitoring to establish the presence or significance of health problem indicator;

- *Health advice or education* included, for example information and advice about healthy eating and weight loss;

**Table 8 Identified need at first health check and access to services.**

Healthcare need in relation to:	Concern noted * N (%)	Evidence of access to healthcare N			
		Excellent	Good	Poor	None
Family history	1 (3%)	-	-	-	1
Medical history	5 (15%)	3	1	-	1
Smoking	1 (3%)	1	-	-	-
Alcohol consumption	0	-	-	-	-
Weight	16 (47%)	9	-	2	5
BMI**	10 (29%)	5	-	1	4
Blood pressure	3 (9%)	3	-	-	-
Pulse	0	-	-	-	-
Urine test	2 (6%)	2	-	-	-
Blood sample test	6 (18%)	5	1	-	-
Thyroid function test	2 (6%)	2	-	-	-
Cholesterol level test	3 (9%)	3	-	-	-
Immunisation status	11 (32%)	9	2	-	-
Ears (wax)	3 (9%)	-	2	1	-
Diet	11 (32%)	6	1	1	3
Exercise level	5 (15%)	2	-	1	2
Sleep pattern	0	-	-	-	-
Skin	1 (3%)	1	-	-	-
Feet	2 (6%)	2	-	-	-
Allergies	0	-	-	-	-
Contraception	2 (6%)	2	-	-	-
Continence	7 (21%)	4	2	-	1
Dental health	3 (9%)	2	-	-	1
Sight	13 (38%)	6	4	1	2
Hearing	7 (21%)	3	-	3	1
Epilepsy status	4 (12%)	3	1	-	-
Asthma	0	-	-	-	-
Mobility	2 (6%)	1	-	-	1
Medicine review	0	-	-	-	-
Feeding	1 (3%)	1	-	-	-
Mental health / behaviour problems	5 (15%)	4	-	-	1

(\* N=34 for family history to exercise; N=33 for sleep to mental health; \*\*BMI collapsed with weight in further analysis)

- *Recommendations* that the person (with support) should make an appointment for further testing or assessment, for example a sight test or dental examination;
- *Direct referrals* made for further assessment and/or treatment of a health problem, for example to the GP, Joint Learning Disabilities Team or Psychiatry, and
- *Treatment* for a health condition that was initiated, for example a cream given to treat a skin condition.

An additional factor that could affect access to healthcare is the proximity of the intended healthcare access point to the health check itself. For example, healthcare that can be given within the health check clinic arguably has a greater chance of occurring than that requiring onward referral only occurring in the longer term, often months or even a year later, when any number of extraneous factors may intervene resulting in a failure to gain access to services. Table 9 below shows the relationship between the timing and type of access required in relation to identified need, and the quality of the evidence that access was achieved.

**Table 9 Access to healthcare services in response to identified health needs by quality of evidence (N=17)**

Quality of evidence	Timing of action*	Prevent	Advise	Recommend	Refer	Treat	Totals
Excellent	Immediate	9	15			1	74 (76%)
	Short Term	17	3	2	14	1	
	Long Term	1		3	8		
Good	Immediate	2	2				14 (14%)
	Short Term	1		3	2		
	Long Term			3	1		
Poor	Immediate		3				9 (9%)
	Short Term			2			
	Long Term			4			
Totals		30 (31%)	23 (24%)	17 (17%)	25 (26%)	2 (2%)	97

\* Notes indicate healthcare access: Immediate – the same day as the health check; Short term – occurred within days or up to approx. 8 weeks of the health check; Long term – occurred several months to a year after the health check

Where evidence is rated 'excellent' we can be confident that the person concerned accessed healthcare services in relation to a specific health issue. Table 9 shows that in 76% of cases needs identified within health checks resulted in access to appropriate healthcare services, and in another 14% of cases there is strong evidence that access was likely to have been achieved. Twenty seven cases of need for preventative healthcare were successful in accessing services (90%), as were 18 cases of need for health advice (78%) and 22 cases needing direct referrals (88%). In cases where there was a need for practice nurse treatment these were met within the consultation. However, in only 5 cases (29%) can we be confident that identified needs addressed by recommending a course of further action by the person with learning disabilities (with support), actually resulted in access to healthcare.

The nature of the health check clinic, as a nurse led service, meant that immediate access to healthcare could only occur where needs could be met by the nurses running the clinic and therefore comprised almost exclusively preventative healthcare or health education and advice. Healthcare accessed in the short term was also largely preventative in nature but also included a number of referrals to other services. Healthcare access in the longer term comprised recommendations to individuals and referrals by the nurses to other services.

For the 3 women for whom there were concerns around cervical screening, all were noted as having excellent follow up evidence. For one woman it was noted that her smear tests had been discontinued and on a later health check it was established that she was not sexually active. For a second woman her name had been removed from the screening register because she found the process too distressing. The third woman attended for a smear test 8 months after her initial health check and was advised at her second health check to attend for another test when it was due.

As a result of their first health check 17 people (50%) were referred on to other healthcare services for 25 identified health needs. In 22 instances (88%) the person was confirmed as successfully accessing services in relation to these health needs. Of the 3 referrals to audiology, 2 people accessed the service while one person refused an appointment. Three of the 5 referrals to the GP were successful. Successful access comprised referrals in relation to hypothyroidism, chronic obstructive pulmonary disease, and dyspepsia requiring helicobacter eradication therapy. Two referred cases where access could not be confirmed were in relation to ear wax and pre-menopausal symptoms. Two referrals to the JLDT were successful in accessing an exercise programme and mental health support. Three referrals to

the CLDN were successful in accessing support to attend an appointment with an optician, behaviour support, continence advice and dentist. Two referrals to a consultant psychiatrist in relation to epilepsy were successful, as were single referrals to an optician, continence advisor and practice nurse. Single referrals to a dietician, podiatrist and the community dental practitioner could not be confirmed as successfully accessed, however appointments were arranged.

**Identified health needs not addressed**

For 14 people with learning disabilities (41%) one or more health issues were noted as a concern but there was no evidence of follow up. Further scrutiny of audit notes suggested a number of reasons for this as listed below (Table 10).

**Table 10 Reasons for non-follow up of identified health needs**

<b>Reason</b>	<b>Condition not followed up</b>
Condition minor compared to other health problems (N=3)	Weight/BMI Diet Mobility
Existing managed health problem (N=3)	Continence Hearing Mental health/behaviour
Severity of disability limits intervention options (N=2)	Weight/BMI Diet Exercise Sight
Already taking appropriate action (N=2)	Weight/BMI Dental
No current signs or symptoms (N=2)	Family history Medical history

For only two of the fourteen individuals was there no apparent explanation for failure to follow up an identified health need. These apparently unmet needs therefore may arise because no specified system is in place to record why follow up is unnecessary, undesirable or not possible.

**3.1.2 Second health checks**

Eighteen (53%) of the patients whose notes were audited had attended three or more health checks. This allowed examination of second health check notes and subsequent access to health care for these individuals because an adequate amount of time had elapsed between their second health check and the audit for access to healthcare services in response to

identified health needs to have occurred. Examination of second health checks allows exploration of the extent to which continuing health checks act to identify emergent, or 'missed' health needs or monitor those identified in the initial health check. That is, to what extent do health checks need to be conducted on a regular basis, as opposed to episodically where circumstances suggest a particular need, for example at transition points in the person's life.

### **Participants**

This subgroup comprised 14 men (78%) and 4 women, registered with three different practices within the PCT. Nine people (50%) lived with their families, 2 (11%) lived independently and 7 (39%) in community provision. Their ages ranged from 31 to 72 years (mean 47.61, SD 9.912). Five of the group (28%) had a mild learning disability, 6 (33%) had moderate learning disabilities and 7 (39%) had severe or profound learning disabilities. In terms of additional problems, 5 people (28%) had none, 5 (28%) had one problem, 4 (22%) had 2, and 4 (22%) had 3 additional problems.

**Table 11 Additional health problems amongst subgroup of people with learning disabilities who had three or more health checks**

<b>Additional Problem</b>	<b>No. (%)</b>
Visually impairment	0
Hearing impairment	1 (6%)
Physical disabilities	4 (22%)
Autistic spectrum disorders	2 (11%)
Dementia	0
Mental illness (Dual diagnosis)	6 (33%)
Challenging behaviour	3 (17%)
Complex health needs	5 (28%)

Overall the characteristics of subgroup are very similar to those of the whole sample with only small differences in terms of more people having moderate as opposed to severe/profound learning disabilities and a greater incidence of mental illness or challenging behaviour. The subgroup was therefore deemed to be representative of the group as a whole. Table 12



below compares the health areas checked and concerns noted at initial and second health checks for the subgroup.

**Table 12 Comparison of health areas recorded as checked and as a concern at first and second health check clinics**

Healthcare need in relation to:	Checked at 1st health check (%) (N*)	Checked at 2 <sup>nd</sup> health check (N=18)	Concern noted 1 <sup>st</sup> health check (%) (N*)	Concern noted 2 <sup>nd</sup> health check (%) (N=18)
Family history	2 (11%)	1 (6%)	1 (6%)	0
Medical history	6 (24%)	4 (22%)	4 (22%)	2 (11%)
Smoking	16 (89%)	15 (83%)	0	0
Alcohol consumption	16 (89%)	13 (72%)	0	0
Weight	18 (100%)	18 (100%)	6 (33%)	6 (33%)
BMI	13 (72%)	15 (83%)	4 (22%)	5 (28%)
Blood pressure	15 (83%)	16 (89%)	3 (17%)	3 (17%)
Pulse	0	0	0	0
Urine test	12 (67%)	13 (72%)	1 (6%)	2 (11%)
Blood sample test	2 (11%)	3 (17%)	2 (11%)	3 (17%)
Thyroid function test	1 (6%)	1 (6%)	1 (6%)	1 (6%)
Cholesterol level test	1 (6%)	0	1 (6%)	0
Immunisation status	10 (56%)	7 (39%)	8 (44%)	6 (33%)
Ears (wax)	2 (11%)	4 (22%)	2 (11%)	4 (22%)
Diet	14 (78%)	17 (94%)	4 (22%)	3 (17%)
Exercise level	17 (94%)	17 (94%)	3 (17%)	6 (33%)
Sleep pattern	1 (6%)	0	0	0
Skin	1 (6%)	0	1 (6%)	0
Feet	8 (44%)	3 (17%)	1 (6%)	0
Allergies	1 (6%)	1 (6%)	0	0
Contraception	1 (6%)	1 (6%)	0	0
Continence	8 (44%)	8 (44%)	3 (17%)	3 (17%)
Dental health	8 (44%)	6 (33%)	2 (11%)	0
Sight	12 (67%)	12 (67%)	8 (44%)	3 (17%)
Hearing	9 (50%)	6 (33%)	4 (22%)	2 (11%)
Epilepsy status	8 (44%)	4 (22%)	2 (11%)	2 (11%)
Asthma	0	0	0	0
Mobility	2 (11%)	2 (11%)	0	1 (6%)
Medicine review	8 (44%)	4 (22%)	0	0
Feeding	1 (6%)	1 (6%)	0	1 (6%)
Mental health / behaviour problems	6 (33%)	6 (33%)	2 (11%)	1 (6%)

(\* N= 34 for family history to exercise, then N=33 for sleep to mental health/behaviour)

Table 12 suggests a similar range of checks were carried out at first and second clinics, and in many areas similar numbers of unmet health needs were identified. In 19 of the 31 areas of health covered approximately the same number of people were checked (+/- 1 person). The only 'significant' exceptions (difference of 4 or more people) was a reduction in numbers checked for foot problems and epilepsy status, and in those whose medication was reviewed. The table also appears to show that blood tests and ear checks were carried out only where there were already concerns, that is, in both cases the numbers checked and raising concern are the same.

Health areas such as weight, exercise and blood pressure tended to be checked at both appointments (18,16 and 14 people checked respectively). Areas less likely to be checked at either health check included conditions such as asthma, and allergies (18 and 17 people respectively did not receive a check at either appointment), and screening tests such as general blood tests and those for cholesterol or thyroid problems (15, 17 and 17 people respectively were not screened in this way at either appointment).

The data was examined for evidence of how health needs changed between first and second health checks. The time lapse between health checks for the subgroup ranged from 14 to 40 months (mean 25.28, SD 5.13). The number of health conditions checked during initial health checks ranged from 5 to 22 (mean 11.22, SD 4.14) while for second health checks they ranged between 6 and 15 conditions checked (mean 10.17, SD 2.64). The small difference between means suggests that the majority of people had a similar number of areas checked at initial and second health checks, while those who had a larger number of areas checked at initial health checks experienced a substantial reduction in areas checked at the second clinic (as evidenced by the fall in both range and standard deviation (SD)). The number of health concerns noted at initial checks ranged from 1 to 7 (mean 3.28, SD 1.90) compared with 0 to 10 conditions causing concern at second health checks (mean 2.61, SD 2.77). These differences show a greater range of health concerns noted for some at their second health check, though mean number of health concerns noted are again quite similar.

Four people (22%) had no recorded unmet health needs at their second check, whereas every person in the subgroup had one or more health needs identified at their first health check. 14 people (78%) had one or more health concerns noted at their second health check, two of whom (11%) had the same number of health needs identified at both checks, 9 people (50%) had fewer, and 7 (39%) had more health concerns at their second check. Table 13, overleaf, shows how recorded health needs changed between first and second

health checks for the subgroup. 'Emergent health concerns' refer to individuals for whom the health area was not identified as a concern at the initial check (not checked, not detected or not a problem) but was so noted at the second. 'Continuing health concerns' were those noted at both health checks, and 'improved' refers to individuals for whom a health area was of concern at their first health check but not so noted at the second check.

This data suggests a variable picture over time though there appears some evidence of an improvement in access to healthcare/health status. Four people (22%) had no recorded unmet health needs at their second health check, and amongst the remaining 13, 34 health issues were no longer a recorded as a concern. The latter health 'improvement' suggest that they have either been successfully managed or resolved. However, it is also possible that such concerns were merely missed at the second check. These issues are discussed further below.

Persistent health concerns are evident, particularly in relation to weight, blood pressure, diet and exercise all of which are associated with risk of serious disease and therefore worthy of regular monitoring. In addition new health issues also emerged in the second health clinic, again this may either be because the person's health had deteriorated in the intervening period or because the condition was not identified at the first health check. Either explanation supports the case for health checks to be conducted on a regular as opposed to episodic basis.

**Table 13 Comparison of identified health needs between first and second health checks (N=18)**

<b>Healthcare need in relation to:</b>	<b>Emergent health need (n=10)</b>	<b>Continuing health need (n=11)</b>	<b>Improved no longer an identified need* (n=15)</b>
Family history	0	0	1 (6%)
Medical history	2 (11%)	0	4 (22%)
Smoking	0	0	0
Alcohol consumption	0	0	0
Weight	3 (17%)	3 (17%)	3 (17%)
BMI**	3 (17%)	2 (11%)	2 (11%)
Blood pressure	1 (6%)	2 (11%)	1 (6%)
Pulse	0	0	0
Urine test	2 (11%)	0	1 (6%)
Blood sample test	1 (6%)	2 (11%)	0
Thyroid function test	0	1 (6%)	0
Cholesterol level test	0	0	1 (6%)
Immunisation status	1 (6%)	5 (28%)	3 (17%)
Ears (wax)	2 (11%)	2 (11%)	0
Diet	1 (6%)	2 (11%)	2 (11%)
Exercise level	3 (17%)	3 (17%)	0
Sleep pattern	0	0	0
Skin	0	0	1 (6%)
Feet	0	0	1 (6%)
Allergies	0	0	0
Contraception	0	0	0
Continence	1 (6%)	2 (11%)	1 (6%)
Dental health	0	0	2 (11%)
Sight	1 (6%)	2 (11%)	6 (33%)
Hearing	0	2 (11%)	2 (11%)
Epilepsy status	1 (6%)	1 (6%)	1 (6%)
Asthma	0	0	0
Mobility	1 (6%)	0	0
Medicine review	0	0	0
Feeding	1 (6%)	0	0
Mental health / behaviour problems	1 (6%)	0	2 (11%)
<b>Total</b>	<b>25</b>	<b>29</b>	<b>34</b>

(\* 45 of 62 health needs (73%) causing concern at first health check were investigated at the second, for the remainder no was check recorded but included here because lack of written evidence was taken to imply that this aspect of health was not causing concern; \*\* BMI collapsed with weight in further analyses)

## **Access to healthcare**

49 health concerns were noted during second health checks and 40 (82%) were recorded as having some follow up action taken. This is a very similar percentage follow up as was noted for the whole group in an earlier analysis (page 25). Health needs identified and the quality of evidence of the follow up action are shown in table 14 below.

**Table 14 Health needs identified at second health check and quality of evidence (N=18)**

Healthcare need in relation to:	Concern noted * N (%)	Evidence of access to healthcare N			
		Excellent	Good	Poor	None
Family history	0				
Medical history	2 (11%)	1			1
Smoking	0				
Alcohol consumption	0				
Weight	6 (33%)	5			1
Blood pressure	3 (17%)	1	1		1
Pulse	0				
Urine test	2 (11%)	2			
Blood sample test	3 (17%)	3			
Thyroid function test	1 (6%)				1
Cholesterol level test	0				
Immunisation status	6 (33%)	5	1		
Ears (wax)	4 (22%)		2	2	
Diet	3 (17%)	2			1
Exercise level	6 (33%)	4	2		
Sleep pattern	0				
Skin	0				
Feet	0				
Allergies	0				
Contraception	0				
Continence	3 (17%)				3
Dental health	0				
Sight	3 (17%)	2		1	
Hearing	2 (11%)		1	1	
Epilepsy status	2 (11%)	2			
Asthma	0				
Mobility	1 (6%)				1
Medicine review	0				
Feeding	1 (6%)	1			
Mental health / behaviour problems	1 (6%)	1			

The data shows that we may be confident that need identified in health checks resulted in access to healthcare services in 29 out of 40 cases (73%), and that we have good evidence that a further 7 identified needs (18%) were also followed up with access to services. There was no follow up of nine concerns identified (23%). As in the earlier analyses the reasons for this were examined. For all but two health needs (relating to concerns about weight and

diet), there appeared a reasonable explanation why no further action was taken. Using the same categories as noted above (Table 10) these are listed in table 15 below.

**Table 15 Reasons ascribed to lack of follow up of health concerns identified in second health checks**

Reason	Condition not followed up
Condition minor compared to other health problems (N=1)	Mobility
Already taking appropriate action (N=5)	Continenence Thyroid Blood pressure
No current signs or symptoms (N=1)	Medical history

The pattern of circumstances discernable from audit notes confirms the earlier view in relation to first health checks that no follow up action was an arguably reasonable course in certain circumstances. Where action was taken, the types of healthcare services accessed were analysed using the same categories as the earlier analysis (Table 9). Table 16 below shows the types of healthcare received.

**Table 16 Access to healthcare services in response to health need identified in second health checks by quality of evidence (N=14)**

Quality of evidence	Timing of action*	Prevent	Advise	Recommend	Refer	Treat	Totals
Excellent	Immediate	3	9				29 (73%)
	Short Term	3		4	6		
	Long Term	4					
Good	Immediate	1				2	7 (18%)
	Short Term			1	2		
	Long Term	1					
Poor	Immediate						4 (10%)
	Short Term			4			
	Long Term						
Totals		12 (30%)	9 (22.5%)	9 (22.5%)	8 (20%)	2 (5%)	40

As in the first round of health checks, need for preventative healthcare was most often identified with a high likelihood of follow up access to healthcare occurring immediately or in the short term. Health education or advice given within the health check itself was also confirmed as accessed. Six of eight referrals for treatment could also be confirmed as having

occurred with the remaining two having good evidence of follow up. As with the first round of health checks recommendations to seek healthcare from another service could not be confirmed as having occurred in almost half the cases.

Seven people (39%) were referred on to other healthcare services in relation to 8 identified health needs, as a result of their second health check (mean 1.14). This compares to 50% (17 people) of the whole sample who were referred in relation to 25 identified health needs after initial health checks (mean 1.47). Overall then fewer patients were referred to other healthcare services in response to a smaller incidence of health need. In five cases (75%) we could be confident that the person accessed health services in relation to these needs. Four people were referred to the JLDT in response to concerns about levels of physical activity and for one person also about their weight. For one individual this was their second referral to this service after joining an exercise programme after their first health check but then dropping out.

The three remaining people were referred to a gastroenterologist, psychiatrist and GP. All had been referred to mainstream healthcare services after their first health check also, but only one person was referred a second time to the same service. A consultant psychiatrist reviewed this person’s epilepsy and some 3 years later they were removed from the epilepsy register. A second person was referred to a gastroenterologist for review after their medical history was checked. The third was referred to their GP because of concerns about their mental health; they were subsequently given medication for the diagnosed condition.

### 3.1.3 Health outcome

Access to healthcare provides, where appropriate, diagnosis of health conditions and access to treatment. The data were examined to identify any diagnoses made following health checks as an indication that the clinics had a role in improving the health of people with learning disabilities. That is by ensuring that health needs are recognised and access to services obtained, their health problems are correctly managed.

\* Notes indicate healthcare access: Immediate – occurred within the health check; Short term – occurred within days or up to approx. 8 weeks of the health check; Long term – occurred several months to a year

Table 17 Overall describes the pre-existing health conditions of the whole sample of patients with learning disabilities. That is, conditions known before attendance at initial health checks, and those diagnosed either as a consequence of investigations launched at health checks or between checks.

**Table 17 Number of people with learning disabilities with pre-existing and post check health conditions**

Condition	Pre-existing	Diagnosed between health checks	Diagnosed through health check (health check number)	Total
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	(n=24)	(n=6)	(n=8)	
Hearing impairment	2	2		4
Visual impairment	2		1 (HC2)	3
Epilepsy	7		1 (HC1)	7
Mental illness	5	1	1 (HC1)	7
Heart problems	5	2		7
Hypertension	2	1	1 (HC3) 1 (HC2)	5
Hepatitis B	1			1
Thyroid	3	1	1 (HC1)	5
Mobility problem	1		1 (HC3)	2
Incontinence	1		1 (HC1)	2
Asthma	4			4
<b>Total</b>	33	7	8	47

Eight people (24%), or nearly 1 in 4, were recorded as diagnosed with a significant health condition as a result of their health check. In addition two people were diagnosed with heart conditions between health checks. Both had been identified as having weight problems and were being given health education and advice in this regard and one had been identified with hypertension. The table above shows that health conditions were not necessarily diagnosed as a result of an initial health check. Although four people's health condition was identified as a result of their first health check, two more were identified after their second, and two as a result of their third health check. This suggests that identification of health conditions through access to mainstream healthcare services was an ongoing process dependent on regular monitoring over time. The suggestion here is that a single health check is unlikely to reveal all health issues pertinent to any one individual with learning disabilities. If this is the case, repeat health checks over extended periods are less likely to result in the early intervention and preventative healthcare necessary to improve health and prevent avoidable deaths.

### 3.1.4 Summary

These analyses are based on an audit of notes made by the joint learning disability team from practice and team records on individual health checks and on subsequent health investigations or actions. As mentioned above any one health check may cover 31 health

areas (or 33 for women if checks on cervical or breast screening were included). However, in many patient records there was no information as to whether certain health issues had been checked. It was not possible to determine whether this was because the issue had been missed, either by oversight or deliberate targeting of issues regarded as more important or acceptable, or because it was covered but found irrelevant or not a problem then simply not written up in notes. The view was taken that where health issues were identified then it was highly unlikely that no note was made in records at all. What was lacking was not knowledge of health needs identified therefore, but information on the entire range of health issues checked. For completeness it would be preferable to have this information but its lack did not invalidate the study.

The analyses described large numbers of patients as having unmet health needs. Even those returning for a second health check included a majority for whom there were continuing or emerging health concerns. A great deal of this need was for preventative healthcare particularly in relation to diet and exercise, but also in regard to access to immunisation programmes. Messages regarding healthy eating and maintenance of adequate levels of physical activity appear difficult to impart and with this population in particular need regular repetition to ensure they remain fresh.

The evidence described above suggests a need for regular health check clinics because of the ongoing nature of health need identification in this population. Similar patterns of health checks were carried out at first and second health checks with some health issues actively addressed at both checks but others seemingly only addressed in response to existing concerns. The reasons why all areas were not checked systematically may lie in that the health check protocols are very comprehensive, covering thirty one main and two women's health issues as well as carer and occupation checks. There was unlikely to have been sufficient time, even with half hour appointments, to cover every area with every person. Where a person is reluctant to submit themselves to health investigations, repeat checks are necessary to build relationships and trust in the process. It makes logical sense to tailor health checks to the needs of the person, however tailoring is likely only to be achieved in the longer term as increasing numbers of health issues are covered, trust and confidence in the process are achieved and the health status of the individual becomes clear.

The answer to the question of whether health checks facilitate access to mainstream healthcare services needs a more wide ranging study than this pilot. However based on the data presented here the signs are favourable. This study suggests that in 3 out of 4 cases,

where a referral is made, the person gains access to services to meet their health need. In terms of meeting needs for preventative healthcare and health advice and education the results are even more impressive with 90% or more of needs for this type of healthcare being met.

## **3.2 Interview Study Results**

### **3.2.1 Awareness of Policy**

#### ***Valuing People***

Seven of the eight practice managers interviewed commented on the white paper 'Valuing People' (DH, 2000), however at best they were only aware of its contents in relation to the requirement to identify registered patients with learning disabilities (N=2), one manager had not heard of it at all. The remaining managers were familiar with the title of the document but not its contents. It is not surprising that practice managers struggle to remember the gist of the plethora of initiatives and directives issued regarding the delivery of general practitioner or primary care services. However, if these professionals are to be expected to follow advice and directives it is important that they are presented in such a way as to become visible amongst both the 'run of the mill' and incentivised schemes.

#### ***GMS Contract***

As the interviews took place in late 2004 compliance with the GMS contract was foremost in the minds of the practice managers taking part. Seven practice managers spoke about the impact of the contract on the practice. Three commented on the extra work and pressure all practice staff felt under while getting the practice ready to commence the contract. They all felt that the incentive structure heavily influenced practice priorities, forcing choices as to what to cut in an effort to both meet legal requirements and maximise practice income from meeting quality targets, which quickly become the practice's 'top ten'

*". . . it's really, really difficult to, to balance what you are contracted legally to do and what brings income into the practice against what you know is good customer care, and good practice, and a worthwhile exercise. And as a manager it's hard to, to sort of think we've got to do all this, but we really want to do this."*  
*(Practice Manager 10)*

Some managers felt that health check for patients with learning disabilities provided an opportunity to ensure that, where appropriate, health promotion activities such as blood pressure monitoring and smoking cessation advice, which are included in the GMS contract Quality Outcome Framework (QOF) targets, are undertaken. Two considered the health checks very helpful in terms of identifying carers, also a target in the new contract. However one manager commented that the number of people with learning disabilities registered was so small that they did not impact on activities attracting extra income to the practice. Two further managers doubted the significance of the contract to the practice in the long-run.

*"The GMS contract is a guide. That's not sort of your.. your Bible as to how you, you know, it's just a guide as to what services you need to target, but every service eventually you need to address."*

*(Practice Manager 3)*

Another manager felt that the current initiative was yet another phase in service organisation that would pass, much the way fund holding had done.

*"I've been here, like I say I've been here 15 years, I've seen it change that many times, I just don't think it's that ... the service for the people will always be here."*

*(Practice Manager 8)*

The only doctor interviewed as part of the study also commented that the introduction of incentives was likely to skew the care provided towards targeted activities because practices need the resources they would bring. He felt that the healthcare needs of people with learning disabilities had been overlooked in the contract. Learning disability nurses also felt that the contract was a disadvantage in terms of their attempts to improve access to healthcare for this group because it made their needs a lower priority for practices.

*". . . as far as I'm aware, there are nothing in the targets for GPs that come from the PCT about health promotion for people with learning disabilities. So they have other targets to meet, which obviously for them are a priority."*

*(Learning disabilities team leader)*

Learning disabilities professionals were unsure of the directives in the GMS contract and the extent to which health checks for people with learning disabilities had any role in meeting contract obligations.

*". . . we need help really. And, from within the PCT to help us to say "Well this is how*

*you can sell it. This is how you can maximise your opportunities with your GMS colleagues"  
I don't really understand it, most of us don't really in learning disabilities."*

*(Learning disabilities team leader)*

As this is a specialist service it is perhaps unsurprising that, much as mainstream health professionals had a vague grasp of the 'Valuing People' white paper, initiatives aimed at colleagues in mainstream were unclear to the learning disability team.

*"I'm supposed to be the resource person to understand, you know, the GMS contract.  
And I guess, again, I probably have a loose understanding of what that is, but . . . I'm  
sure I don't know what the impact of that, and what the consequences might be for  
the population that I'm supposed to serve, . . . it's actually on my list of things to do  
to find out more about the GMS contract."*

*(Learning Disabilities Service Manager)*

Practices were therefore getting to grips with their responsibilities under the new GMS contract, albeit in some managers' view yet another in a long line of initiatives that would eventually be superseded. Practice and learning disability staff agreed that the contract did not directly address the health needs of the group although some aspects of some people's health need would fall under certain targets within the contract. Learning disability managers believed that better understanding of the contract could facilitate their own practice.

### *1.3 National Service Frameworks (NSFs)*

Practice managers and nurses were aware of the range of NSFs published, however these guidelines to practice tended to be a secondary priority depending on their relevance to the GMS contract. One practice manager acknowledged that some people with learning disabilities will fall into some of the NSF categories but felt that these would not entirely meet their needs. A practice nurse felt that as a group they needed to be specifically targeted.

*"I think this group of people missed out again with that. I just think it would be better if  
they had a, something, they've got something for people with mental health . . . the NSF  
for the elderly and all these other things but I think they would've been far better to  
have their own."*

*(Practice Nurse 6a)*

Nurses and managers from the joint learning disability team also had a tenuous grasp on the guidance in the NSFs and their applicability to their target population.

*" . . . I'm familiar with how the bits that we're involved in fit in, you know, around the children's NSF and the development of children's trusts and transition . . . But I probably don't have the time and other forums to be as fully au fait with what's going on in NSFs as I should be."* (Learning disabilities team manager)

*"[We need to] increase our awareness of those areas. Because I was surprised how many people are being put onto, . . . had been registered in different ways. I don't think the [learning disability] nurses were aware of that."* (Learning disabilities team leader)

As with the GMS contract therefore only certain individual's needs were seen as likely to be met by particular frameworks while other would not be addressed at all.

### **3.3.2 Awareness of patients with learning disabilities**

#### ***Prevalence of patients with learning disabilities***

Practice managers and nurses stated that they were not on the whole aware of the number of patients registered who had a learning disability before the implementation of the programme. In smaller practices the manager might be aware of some patients if they attended regularly.

*" . . . I mean the ones we are aware of are frequent attenders. So they obviously know how to access the service. And the staff are aware of some of our patients with learning difficulties, and we do deal with them more sensitively really . . . "* (Practice Manager 3)

One practice manager stated that she was aware of some patients with learning disabilities, but in the main this was because at that time the learning disability nurses were based in the same building. Contact with these patients tended to be with their GPs and not the practice nurses.

*" . . . when they were, you know, identified with the health check, a lot of the doctors are very familiar with the people involved because they've been involved with the care for many years. So it's not that they weren't receiving the care necessarily, it's just that we hadn't thought of them as a group. You know, to be targeted."* (Practice Manager 8)

Lack of awareness of patients with learning disabilities as a group was reflected also in the experience of learning disability nurses approaching practices with a view to setting up a programme, although there were exceptions.

*"... one of my colleagues was talking with [a practice] about setting up a health check programme, and when they identified their clients that would, they would be inviting in, . . . . all these people that were identified had been in within the last six months to see the practice nurse. But that was unusual."* (Learning disabilities team leader)

Practices were therefore aware of some patients with learning disabilities, generally those who attended most frequently. Practice nurses had fewer contact with these patients than general practitioners.

### **Access to general practice**

Four practice managers and four practice nurses stated that they believed that patients with learning disabilities had the same access to general practice services as everyone else, however two also acknowledged that these patients may not be aware of the services offered.

*"It's just that because of their disabilities, they're maybe not aware of this, especially if they're mentally disabled as well. . . . . I mean a certain patient with mental problems might be quite aware and might be able to get to the GPs and some can't, can they?"* (Practice Nurse 10)

Several nurses made comments on the role of carers in facilitating access to general practice for people with learning disabilities. Comments from two nurses suggested that they did not feel the practice had a role in ensuring patients with learning disabilities used their service.

*"[Patients] have to take some responsibility. Perhaps if, if they have learning disabilities and they can't take their own responsibility, then they must have a carer or somebody who takes responsibility for them anyway."* (Practice Nurse 3)

*"I think some used to come anyway, but if they're dependent on their carers or their relatives, then obviously they can't just come in on their own, they have to be brought, so if the carers don't feel it's necessary then they needn't be brought."* (Practice Nurse 8)

Three practice managers felt that their attempts to inform these patients about services had been poor in the past, as they were sent the same letters as non-disabled patients.

*"I think all information was geared at the average person and then I think you've got the obvious ones like, other languages and perhaps for deaf people and people who have seeing . . . . and I don't think learning disabilities was as focussed perhaps at that time as those other specialist areas."*

*(Practice Manager 2)*

In practices the general view therefore seemed to be that the services were equally available to patients with learning disabilities as non-disabled patients. It was recognised that access to the practice was often mediated by a carer and that information about services may not be accessible to patients with learning disabilities.

### **3.2.3 The Health Check Programme**

#### ***Development***

A doctor at the practice that first implemented health checks described a period when his practice had begun to adopt a more pro-active role by offering health promotion to patients. He became aware, however, that patients with learning disabilities did not appear to be accessing the practice and so sought to provide health promotion opportunities in a more structured way. The learning disability service professionals confirm that the development of the programme emerged from this initiative in general practice.

*". . . it was.. that relationship with the [initiating] Practice really that kicked that off. . . . what has enhanced it is moving out into localities and having a dedicated multi-disciplinary team within our localities."*

*(Learning disability team manager)*

However the path forward was not entirely clear in the beginning.

*"we've always wanted to do [health checks] with the practices and with the GPs, and I think it took us a while to understand that it wasn't a role that GPs themselves were going to be able to undertake, it was going to be one that they would delegate through their treatment rooms and treatment room nurses or practice nurses."*

*(Learning disability team manager)*

As the team moved out into localities learning disability nurses were linked with particular practices. Development of the programme was initially envisaged as being integrated into the workload of these nurses.



*" . . the reality is.. is that the work is very, very pressured, and... [setting up health check programmes is] perceived as development, and to actually do that outside of your ordinary caseload, which is high and complex now because the profile of casework is changing, and they were just not being able to practically find the time to do that in their localities."* (Learning disabilities team manager)

Progress in introducing health check programmes to new practices was therefore very slow. In addition, not all learning disability nurses were comfortable with this new development role.

*". . . it is constantly sort of negotiating that, selling that, trying to get them onboard, trying to identify what it is we can achieve for them in their targets, or in their performance indicators by investing in it with them."* (Learning disabilities team manager)

*"I would far prefer it was coming from a more equal point of view, you know, that they were equally concerned and aware of the issues, and wanting to set up these things and maybe you know, relished or wanted the help of our specialised services, which is what it should be really. But I didn't feel, it was very, very one-sided."* (Learning disabilities nurse 3)

This difficulty was overcome by appointing one person to lead on implementing the health check programme. A nurse, who was completing an MSc, negotiated with his employers to be allowed the time to develop the health check model and facilitate implementation partly to satisfy course requirements. This arrangement met the nurse's needs and overcame difficulties arising from giving an unaccustomed and sometimes uncomfortable role to all learning disability nurses.

*"[I was] asked to get involved, so that's how I became aware of it. And then I started doing some post-grad study at [the] University, and I was looking for a research project and so it's, . . . . And I saw that this was really a simple model that could make such a huge difference if we were able to repeat it across the borough."* (Learning disability team leader)

This nurse was given permission to use half of his time to develop the programme. Following reorganisation within the team another nurse now has a half time post to continue the work.

Both perception of the format of health checks, from GP to nurse led, and programme development methods, from a role for all learning disability nurses to one for a specific nurse,

changed with experience in interacting with, and implementing the programme in general practice.

### ***Reasons to implement health checks***

The learning disability health professionals were quite clear in their belief in the usefulness of health checks in improving access to healthcare, including health promotion and prevention activities, in an effort to improve overall health and avoid unnecessary distress.

*"Certainly when somebody goes into hospital as an emergency, it's distressing for the patient and for the carers and is very often a very difficult situation to manage within the hospital, . . . . And very often that can, you know, could have been avoided if that person had been having regular checks to see if their, for example with epilepsy if their blood levels were okay. And not waiting until it becomes toxic and then causing all that distress."*

*(Learning disabilities team leader)*

The practices, described a number of reasons for taking on this health promotion activity including establishing contact with less frequent attendees; improving customer care; ensuring certain individuals are not neglected; and/or addressing the needs of this marginalized group.

*"We're trying to ensure that all patients who, who fall into this category, get a regular check-up. In order to, to get the ones that don't come in more frequently"*

*(Practice Manager 10)*

*". . . we thought it was a good idea because this particular group of patients, you know, they shouldn't be neglected. They've got special needs and we wanted to invite them in to see what those needs were."*

*(Practice Manager 5)*

In addition, certain practice managers or nurses expressed additional reasons for implementing health checks, including allowing registered patients with learning disabilities to benefit from contact with, and advice from the Joint Learning Disability Team (JLDT); to provide a holistic rather than disease specific consideration of patient needs, as happened in other clinics; to offer people with learning disabilities a longer appointment so that they could discuss their needs at length; and interestingly, as a way to make contact with carers.

*". . the carer is often able to give us information that the person themself, themselves [can't], and also it's a way of speaking to the carer and see if they have any needs to address."*

*(Practice Manager 10)*

*" People don't get that long an appointment. . . . it's a luxury to have half an hour to talk about yourself, but it's not a luxury to people who need half an hour to talk about themselves."*

*(Practice Manager 6)*

At another practice these clinics were not considered something 'special' or 'extra', just facilitation, because they offered health checks to all their patients.

*"I mean, it didn't matter because we are supposed to do health checks on everybody if they want anyway, irrespective if they're learning disabilities or not, you know what I mean. It was no sort of discrimination there, it's just that, if anybody wants to have a health check, they can have one. So it's something we would be doing."*

*(Practice Nurse 8)*

Not all practices approached were keen to take on this programme however. For some practices this view was taken because other activity within the practice, such as building work or having just taken on a new practice nurse, meant that the timing was not appropriate. However other practices did not view provision of this type of clinic a priority.

*" one practice . . . worked with us to identify the patients, and one of them had 30 patients with learning disability that were identified. But when it came to the stage – "Well let's work together and offer them health checks" they said "No", it wasn't a priority for them at that particular time. And that was very frustrating really because there was nothing we could do about it, we didn't have any way to appeal against that or ... We just had to accept what they said.."*

*(Learning disabilities team leader)*

*". . . it's proactive surveillance health screening, . . .the model that we've chosen. And I think the difficulty within the medical profession, or primary care as a setting is that... proactive surveillance is [seen as] useful if your history says that you're predisposed to something, you know, . . . they don't see the value in proactive surveillance for the learning disabled client group"*

*(Learning disabilities team manager)*

The learning disabilities team worked from the premise that communication difficulties mean that expression of health needs is often inadequate among people with learning disabilities.

*". . . so many things have the potential to go unrecognised even though people [with learning disabilities] are surrounded by support, because, you know, they can't communicate those internal changes in their body or their pain threshold . . ."*

*to someone, to say, "Oh actually, you know, . . . I've been feeling ropey for six months."  
So that's the value for me of it. Sometimes it is hard to convince primary care that,  
you know, . . . [that] that's the predisposing factor ..."*

*(Learning disabilities team manager)*

A common explanation for the decision not to offer health check clinics is that the health promotion and prevention activities can be done opportunistically.

*". . . when people say that it can be done opportunistically, it can be, and it does work sometimes. It, the assumption is there that people are gonna come in when they're not well, or that somebody's helped them to realise that they've got a health problem. . . . yet very often people are not able to explain that they're in pain or that they're not feeling very well. Often it's assumed to be something else, and so that may not always work - waiting for somebody just to come in."*

*(Learning disabilities team leader)*

Outright refusals to implement the health check programme were few and the learning disability nurse responsible for leading on the programme attributes this to the simplicity of the model.

*". . . it's a very simple five step, four or five step process that we use. . . . so it's quite a clear process. So I think it worked pretty much the same within every practice. . . . their fear is that they're going to get involved in something that's going to, you know, absorb lots of their time."*

*(Learning disabilities team leader)*

Practices were therefore concerned to ensure their patients with learning disabilities were not disadvantaged and running health check clinics was a means to address their concerns or facilitate provision of a well-person check to which they were deemed entitled as a matter of course. Few practices declined to implement the programme however explanations of reluctance from the learning disability team managers' perspective appeared to centre around identifying the 'risk factor' for the group. For the learning disability service this was founded in the cognitive and communication problems faced by this population, which meant identification of need and help seeking activities were compromised.

### ***The Decision to Implement the Programme***

In seven of the practices the decision to implement health check clinics for patients with learning disabilities was reached by agreement amongst the whole practice.

*"It was a group decision really. We had the initial meeting, we would have brought it up at a clinical meeting or a practice meeting just to confirm, you know, if everybody wanted to go ahead, and there weren't any objections."*

*(Practice Manager 3)*

*"When I received this letter, you know, I thought well, yeh, I would like to, em, be able to offer that service for them so I did ask the GP and the GP's have been quite happy for me to do that, they said "yeh, go ahead".*

*(Practice Nurse 9)*

In two practices the practice nurse alone made the decision to go ahead.

*" I just agreed it. I agreed that I would do it. I thought, can't see a reason why not, so I just did it. . . . I knew they (the GPs) wouldn't mind. I knew they wouldn't be opposed to it, so ... because that's our job, that's our duty really. So just went ahead and did it. "*

*(Practice Nurse 8)*

In four of the remaining practices the practice nurse had taken the lead on proposing the practice initiated the checks. Practice managers and nurses reported that the GPs were happy for the nurses to run these health check clinics and in only one practice was limitations on practice nurse time an issue.

*"The GP didn't feel as if he wanted to do it. I felt as if there was a need to do it but the only time I could do it was in my own time. . . . He was quite happy for me to get involved. I think he didn't, perhaps he didn't personally want to get involved."*

*(Practice Nurse 4)*

Three of the practice nurses interviewed had not been involved in the decision to implement the health check programme, this had fallen to a senior nurse. Once agreement had been reached they were informed and arrangements were made with a community nurse from the JLDT to begin the process of setting up the clinics.

### ***Apprehensions about running clinics for patients with learning disabilities.***

Practice managers and nurses described few apprehensions about the clinics prior to implementation. Two managers expressed concerns about whether there would be enough

time to fit these clinics in amongst all the rest of the practice tasks. Two were concerned as to whether the clinics would be a success, whether patients would attend, whether the clinic would prove to be an effective use of time. One manager admitted that she was relieved to discover that the programme was not as intensive as she first believed.

*"I was, about, apprehensive at first, 'cos I wasn't quite sure what she meant. I didn't know she meant if this is going to be something we'd be doing every month, you know, . . . So when she said two years I was thinking "Oh god, that's fine, can't . . .", you know . . . ., I felt we could accommodate it then without too much difficulty."*

*(Practice Manager 7)*

*"... we know that primary care is very busy and they're continually having demands and targets thrust upon them, so we appreciate that. But we found that most practices that wanted to work together with us appreciated that we'd done a lot of their leg work for them. We'd done a project with them, so it's not a matter of giving them extra work, it's doing it with them."*

*(Learning disabilities team leader)*

Practice nurses might be thought to have had more immediate concerns about working with this client group. However four nurses had no apprehensions whatsoever, the concerns of other nurses included whether the standard format of a well-person's check was appropriate for these patients; about communicating effectively with patients without being patronising; having sufficient knowledge of services available for them; and dealing with patients incorrectly labelled as having a learning disability.

*" Probably communication barriers, 'cos you're always worried as a nurse or any professional I think, that you don't miss anything. So I think probably mainly communication. . . that they can't, they couldn't communicate enough to tell you if they was seeing anything or if anything was the matter. "*

*(Practice Nurse 10)*

*"I was worried about just talking to people to say that they'd got a learning disability, if they didn't think they had one."*

*(Practice Nurse 5)*

Apprehensions on the part of practice management therefore centred on time demands. However these proved acceptable. Practice nurses' concerns were understandably about communication and providing appropriate care, but also about dealing with people whose learning disability was mild, or who had been incorrectly identified. Dealing with people who do not accept the label 'learning disability', perhaps even though their learning problems are

significant, and indeed those incorrectly identified may prove stressful for nursing staff. The stigma of the label is such that professions may be unwilling to apply it to more able people with learning disabilities even though to do so would bring extra support they may need.

### **Registers**

The first step in the process of setting up a clinic was to identify patients with learning disabilities. Three practices used personal knowledge alone to produce a list of patients with learning disabilities and two further practices supplemented personal knowledge with computer searches, though these were not very productive. Two practices had well developed computer systems at the time they implemented initial health checks and were able to interrogate their systems using a range of search terms. The remaining two practices relied to a large extent on the list of patients supplied by the JLDT.

*" . . . when we first started, we hadn't been computerised very long, so we, to try to find the patients, we went on personal knowledge of the GPs, learning disability team, receptionists and anybody in the practice who could think of anyone that they thought had learning disabilities."* (Practice Nurse 6a)

*"It wasn't difficult. They just shouted them out and I scribbled them down, and I don't think we've added anybody. I think so, I think we've probably 100% of, unless there's some others in there somewhere that we're not aware of."* (Practice Manager 9)

*" . . . we're a big practice, there's a lot of computers and faffing about to be done, so we have a full time IT person. And he would've done the searches and, and the criteria and so on. . . . . So it would've had to have been very clearly specified, our system is very specific, you can't just say 'about', it's got to be exact. So [the practice nurse] would've had to have given very clear criteria of what kind of disabilities we were looking for. And that would've set the scene..."* (Practice Manager 7)

*"I actually remember the learning disabilities team coming with a list of patients. I actually don't think we did any extra searching."* (Practice Manager 3)

Since these initial health checks however, many practices have developed more comprehensive computer systems. Several were in the process of converting from one system to another, which created some difficulties in relation to read codes as these varied between systems.

*"we've just, with the new computer system we've got a whole different set of recodes. A lot of the codes have changed from a 4 bite to a 5 bite code, its called, so erm, sounds technical. There's thousands of them, so its much more difficult with this system than the other one . . . to find the codes that you want. There's so many more to pick from."*

*(Practice Manager 9)*

Difficulties were described by three practice managers around compiling appropriate search terms to ensure that all patients with learning disabilities in the practice database were identified. However two other managers stated that computerisation would facilitate the maintenance of an up-to-date register as patients moved in and out of the practice.

*"That would form the, the register because it's, it's not a static, 'cos people die, people come on the list, people leave the list. And so, were you to ask me today to find you a, a register, I could run one, given the right information, and give it to you the same, every day, if we had a different patient, or one leave every day. So the register is easy to maintain."*

*(Practice manager 6)*

Computerisation also enabled one practice to cross check to find out whether patients were also on other 'registers'.

*"You can to a degree ask when you do a search, you can ask it for patients that're on more than one registers, you see, you pull that out. So you would ask for that beforehand and you would know then which patient was on, you know, maybe two or three. Odd ones are on three. A lot are on two."*

*(Practice manager 7)*

Other practices had not reached this level of sophistication with their computerisation process.

*"Well this is brand new to us you see, read codes. We're doing it now for the [first time]. But we've, it's quite new. We've not read coded anything up till this year. . . . I don't understand it. I've gone back to paper. I've gone back to using me diary. And I trained people to use computers - 15 year ago, 20 year ago. Now I wouldn't use this one if I had the choice, no."*

*(Practice manager 8)*

The identification system however produced a number of 'false positives', that is people were identified who did not have a significant learning disability.

*"If they're on our list and they're still currently with that practice, we're sure that they've got a learning disability, otherwise we wouldn't have been working*



*with them, so it's clear there. But very often there's ... on the practice list there are people who have mental health problem but there's no learning disability, or they've got dyslexia or other specific learning difficulties.” (Learning disabilities team leader)*

Even though a number of misidentifications were found before invitations were sent out, three practices experienced people arriving for a health check who apparently had no learning disability. These occurrences were rare however.

*“... we had got one young lad who was, came as a patient who may have been, what's the word, a little bit slow at school. But he certainly wasn't mentally disabled and he was working and it was a little bit embarrassing that he should have been put on that list. He certainly wasn't in the category and we both commented on that. He wasn't in the category to go on that list.” (Practice nurse 10)*

*“What I found with the health screening that I did was that there were a few people who came along who.. wouldn't normally access a learning disability service. I think it's that definition of a learning disability that maybe we still need to get some [consistency] really. A couple of the people came access, that came access mental health services . . .” (Learning disabilities nurse 1)*

These situations were handled tactfully, usually with the withdrawal of the learning disabilities nurse and a general health check being conducted by the practice nurse. Computer records were later amended.

Identification of patients within practices was therefore achieved through a number of routes. However the need to adopt computerisation, due to initiatives such as the new GMS contract implies that all practices will have the option to search computerised records to compile patient registers in the future. However, computerisation will not necessarily make identification of patients straightforward due to the array of read codes that might be applied to the records of these patients. Nevertheless once these coding difficulties are resolved, maintenance of these 'virtual' registers was expected to be problem free.

When the programme was implemented it was the first time that practices had actually sought to identify patients with learning disabilities as a group. However the numbers found were small, tending to be between 10 and 40 people depending on practice size. These numbers approximate to between 0.001% to 0.007% of the practice list size, with the largest practices (>10,000) identifying lower proportions of patients as having a learning disabilities,

between 0.001% and 0.003%. The smallest practice in the group (list approximately 2000) reported the largest number of patients with learning disabilities, representing approximately 2% of the list. It is unclear why there should be such a large discrepancy between this practice and others taking part. It is conceivable that variation may exist due to resettlement of large numbers of residents of former mental handicap hospitals into large group network homes in certain localities, however this is likely to be the exception rather than the rule. The practice with the longest experience in conducting health checks (list approximately 3,500) stated that when the programme first started they identified 16 patients with learning disabilities (0.004% of current list) but in the latest round, their fourth, this had risen to 25 (0.007%). This suggests that more patients may be identified over time as practice staff become more aware of them as a group and notes are updated to include specific coding for learning disability.

### ***Programme timing***

There were mixed opinions about whether the biennial timeframe for conducting health checks was appropriate. Three practice managers and four practice nurses felt that an annual health check would be the best option to maximise benefits for patients with learning disabilities. These statements were often qualified with comments that this would be workable providing the numbers of people seen remained the same; provided they were only run for people with identified medical needs; or provided the practice could handle the additional paperwork. Two practice managers and three practice nurses felt that the biennial timeframe was appropriate but again made qualifying statements, for example that they would hope to see these patients between clinics, or this would only be appropriate if the person is generally healthy though it was envisaged that some individuals might lose their confidence in health check procedures (such as having blood pressure checked).

*"Because its small numbers it wouldn't be too big a problem [to have annual health checks], but you're talking about a half hour appointment per person, so if you've got a dozen appointments, what's that, six, six hours isn't it? Which isn't insignificant, but its not a huge volume."*  
(Practice manager 9)

*". . . I think it needs to be seen as a long-term thing. I mean, quite what intervals are desirable, I suppose might be open to debate. . . . there are a lot of people with varied conditions who we look at, you know, who we invite in on an annual basis for a review. . . . I would have thought that [every other year is] fine. I would have thought annual maybe less returns for the work really. . . . especially if it has a knock*

*on effect with people actually seeking more help proactively in between."*

*(General practitioner)*

*"I think a lot can happen in two years and so I would still like to see it annual, unless you've got somebody who you've absolutely no concerns about at all, but I don't know, I think we really do need to see how we go because these are perhaps patients that we wouldn't normally see opportunistically, so I think in two years you can miss a lot."*

*(Practice manager 2)*

*"I'd like to think that really good health action plans would determine in the long term the level of proactive surveillance that an individual needs around their own body, rather than thinking that everybody with a learning disability needs health surveillance on an annual basis or biennial basis. . . . But then, how would you know that they weren't well, 'cos we miss all these signs, you know, so I think it's a difficult one really. And it's one that we do have to be careful with, with primary care, because if we overburden them with something that they see as unnecessary.... but you know, we should be challenged as well as us challenging them really."*

*(Learning disabilities team manager)*

There was therefore much equivocation around the ideal timescale for repeat health check clinics. Biennial clinics being more manageable logistically for hard pressed general practices and perhaps an adequate level of surveillance for people who remain well, or attend other disease specific clinics in tandem. However, the underlying problem of identification of need among people with learning disabilities remains and for this reason the health professionals involved were concerned to leave repeat surveillance for this long.

### ***Clinic timing***

The majority of clinics consisted of 30 minute appointments for four to five people over an afternoon or morning session. The length of time taken in appointments varied with the complexity of the needs of the individual. The shortest appointment times allocated were 16 minutes and longest 45 minutes, the latter being a special arrangement for initial health checks only. Clinics were completed over a number of weeks or months depending on the frequency of sessions. The most intense programmes were run over two sessions a week for three to four weeks (two practices). The least intense programmes were scheduled for one session a month and completion therefore took several months. Other patterns included weekly or bi-monthly sessions.

Clinics were generally slotted into 'open' or 'flexible' time periods where the practice nurses had more autonomy over their workload. At various times these slots might otherwise be

used for home visits, 'flu jab sessions, over 75 health checks or other specialist clinics including those for people with diabetes.

In one practice, clinics were run over two sessions in one day meaning that health checks were conducted on about 10 people with learning disabilities. The nurses involved found this arrangement difficult.

*" . . . for me personally, by the time I've seen, you know, six diabetic patients or six IHD patients or any that's got the same chronic disease, I'm getting that I need a break. . . . I still hope that the first patient gets the same amount of care as what the last patient does but you just feel, you know, yourself that 'I've had enough, I need a break.'"*  
(Practice nurse 10)

*"We don't do special clinics for things apart from diabetes, learning disabilities, children's immunisations maybe. So you know, we have to set special time aside, protected time aside for it. So, which is what we did. It does take a lot longer if you can't do it every week. It's probably better if you can, but it's finding a space in the week to do it."*  
(Practice Nurse 6a)

*" . . . we did it over, I think it was roundabout 3 months, 3 or 4 months, where I just invited 2, 2 in at a time to come inside and did the rest of my work during that working day"*  
(Practice Nurse 9)

Different organisational arrangements therefore suited different practices. However clinics seeing no more than 5 or 6 patients in one day were preferred, as well as spacing clinics to be completed over shorter as opposed to longer timescales.

### ***Invitation to attend***

For all six service users interviewed invitation letters to attend health check clinics were received and read in the first instance by carers. In two cases the recipients were registered blind and therefore cannot access text based communication at all. In one other case the carer described how the person's keyworker would have opened the letter with the person concerned.

*" . . . keyworker opens the letter with the resident and explains and then for the few days leading up to it, we explain that we're going to the*

*doctors for a check up so that they get used to the idea that they're going and they're fine with it." (Carer 102)*

In another a parent described how an initial invitation for a health check was refused because the person concerned already had regular contact with the practice over a health matter. The second invitation was gladly accepted because the CNLD was to attend.

*". . . they'd had a review of patients on their books and sent letters out asking, inviting them to come for a health check. . . . it was just the practice nurse, [so] I didn't feel that we were going to get anything more from that, than he was getting already from seeing the doctor fairly frequently. But when we get a situation where we've got a specialist as well as a practice nurse, then I can see a lot more merit in it." (Carer 202)*

In all cases carers discussed the invitation with the person they cared for to explain what it was for and what would happen. This was to gain consent but also give assurance. Carers reported that they made assumptions about what would happen during the check. For one woman, no mention was made of the check until the day before the appointment this was to ensure that she did not become over excited or stressed about the event because this was likely to trigger an epileptic fit.

*". . . we just explained to her, 'cos we didn't really know ourselves, but we had, I mean with a health check you know they're gonna do basic things so we just explained to her that, you know, she'd be weighed and things like that, which she's used to getting weighed. And she was fine with that and she, she was just, she'd say "Are you coming with me (...)" and I'd say "Well I'm coming with you, yeah" and she was fine, if she knows who's going with her, she was quite ok with that. Yeah." (Carer 102)*

Although this is a limited amount of information it suggests that invitations themselves are not handled by patients with learning disabilities. This may be because parents and carers do not regard them as accessible to the person they care for, even where they incorporate picture symbols. For people who are blind, audio versions of the invitations are need if they are to be accessible for those who have the ability to comprehend the content.

## **Lead**

Health professionals were asked who they considered took the lead on running the health check clinics. One practice manager and three practice nurses considered that there was joint leadership in running the clinics, and three practice nurses felt that their practice now took the lead on setting up and running clinics. Four practice managers and three practice nurses felt that the learning disability team had lead responsibility for running clinics.

*"it's, it's been from both...I suppose now, I suppose really it's the Learning Disabilities Centre that triggered it off because they contact us to say that they, they're ready to do it, are we ready? If they didn't contact us, then we would then be in touch with them . . ."*  
(Practice Manager 10)

*"Because they initiated the thing, (we'd have) forgotten two years later, had they not initiated it again. Although we're responsible for the physical care of the patient. I'm not saying that. I'm not saying I'm pushing responsibility on them, but they seem to be the key person in it."*  
(Practice Nurse 5)

After two or three cycles of health check clinics therefore practices appeared to feel some ownership of the programme, but still regarded the learning disability service to have a significant role in initiating ongoing clinics.

### **Practice Resources**

Implementing health check clinics has implications for the resources available to both the practices and learning disabilities team in terms of accommodation, staff time and consumables. The general practice that initiated the programme was fortunate in having obtained extra funding to set up the first clinic.

*"The first time we did it we did actually have some extra hours from the Medical Audit Advisory Group that there was then, which was paid for by them and that's when we did it. But after that, because we thought it was worthwhile we just found the time to do it, so we did."*  
(Practice Nurse 6a)

Practice managers and nurses agreed that the main resource required from the practice was a room and practice nurse time. In three practices the practice manager was involved in creating the register of people with learning disabilities in the first instance. Practice nurse time is very valuable, however none of the practices reported that implementation of the health checks required inordinate amounts of nurse time. Two practice managers stated that the costs or time of doing these checks could easily be absorbed by the practice (practice list

sizes 3,462 / 2 WTE nurses, 6000/ 1.5 WTE nurses). This is likely to be because of the small numbers of checks required. Where practice managers or nurses were able to offer estimates of the time involved they suggested that the programme was likely to take between 12 and 15 hours of practice nurse time over a number of months, depending on how clinics were organised.

*"Again, if, I, I would say, again from a logistical point of view, if you didn't do a massive checkup every week . . . if you saw three or four a week, we can absorb it. I'm sure any practice could absorb that."* (Practice manager 6)

*"if you only have a nurse for two days a week, that is gonna be a big cost. This is where a big practice has an advantage in that they can absorb it better."* (Practice manager 7)

For one of the largest practices the only issue was that of physical accommodation for the health check clinics.

*". . . we've actually got an accommodation problem here. So we're at the point where we can't employ any additional people to take on additional services, so we are restricted to what we do with the time that we've got because of the facilities. And that's a major impact on every service that we provide at the moment, (...) the doctors' appointments as well, as you might see. That's our biggest barrier."* (Practice manager 3)

One practice manager commented that the resource required was not considered as 'extra' within the practice because patients with learning disabilities were entitled to have a health check.

*"I don't think there's extra expenditure myself. Because everyone's entitled to the same health check. It's not, we wouldn't disregard anyone for a health check, . . . . No, I don't think there's extra expenditure. . . . . We have 10 patients out of 6000 with learning disabilities, even if it goes bigger, it's not our biggest thing you know. So I don't think it will ever cause a problem as "Oh it's costing us too much" or "It's taking too much time"."* (Practice manager 8)

Only one practice nurse found the time commitment unsatisfactory. This nurse was personally committed to providing health checks to patients with learning disabilities but, although the general practitioner lead at the practice was happy for her to do health checks, she was not supported to implement the programme.

*“It was a new area. I think the worst part was having insufficient time to sort of deal with it properly and do the documentation and talk, talk to [the learning disabilities nurse]. And to follow up some of the actions that said it should have been done. . . . I think it's worthwhile doing this for the patients, there's a lot that can be done really, in certain areas and picked up, so I think it is worthwhile. After saying that, you've got to have the staff to do it, you've got to have the time to do it.”*

*(Practice nurse 4)*

### **JLDT Resources**

Practice staff agreed that the larger resource commitment to running the health check programme was borne by the joint learning disability team. However, as noted above, this is a commitment that the team was determined to make. Further implementation, after the initiative from the instigating practice was complete, involved allocating half of a grade G nursing post to leading the programme.

Learning disability nurses described an ongoing process of talking to practices about adopting the programme and then setting up and running clinics. For instance, this might involve three to five telephone calls to the practice before a meeting with practice members could be arranged. This was followed (excluding travelling and waiting time) by a half hour meeting with the practice manager/lead GP and, having secured agreement, a separate hour long meeting with the practice nurse to set up the register and obtain appointment slots. Activities including sending invitation letters and making follow up phone calls to give further information or confirm attendance were likely to take around two hours. This was then followed by attendance at clinics for longer or shorter periods of time depending on the organisation of clinics, however, as with practice nurses this was a time commitment of between 12 to 15 hours on average over a number of months. A total of perhaps 16-19 hours work. This effort is repeated for initial health check clinics at each practice recruited to the programme. Repeat clinics are likely to take less JLDT resource, however still involve updating registers and organising and running clinics in much the same way as for initial clinics. If health checks were to be implemented in all 67 surgeries, using the time estimates above, this could amount to approximately 1072 hours work. From this perspective, operating biennial health checks must be attractive because the time commitment per annum would be halved.

Thus far two practices have created registers of their patients with learning disabilities but have not as yet run any health check clinics and one further practice began the programme



but did not complete. These incomplete programmes also have staff time implications for the learning disability service.

*"There was more than one practice nurse. And I suppose the reason it wasn't completed is that they were limited on time, it wasn't a priority for them, so I don't feel they were really motivated to, to do it at, and initially they did agree to do it."*

*(Learning disability nurse 3)*

In addition, learning disabilities nurses described time spent in training healthcare assistants to assist at clinics by supporting patients with learning disabilities while waiting for their health check (a resource not used in every practice). One learning disability nurse also described preparing some individuals for their check by, for example, helping them to tolerate having a blood pressure check or talking to residential care staff. There is a somewhat blurring of boundaries in this regard as to which activities are very specifically health check related and which naturally form part of the learning disability nurse's workload.

*"Because it is something ... the other thing I spent some time doing as well is talking to staff groups within residential services. Because I think one of the things that other nurses find was that quite often they were the people who weren't turning up for appointments. So really it was sort of explaining to them what the process was and being clear about their responsibility within that as well."* *(Learning disability nurse 1)*

As noted above, early in the development of the programme all learning disability nurses were given targets to try to complete health check clinics in 3 or 4 practices per year. However the demands of their casework meant that they struggled to meet the targets and the service manager decided to revert to a half time dedicated post.

*"Definitely, yes. I think it works better having a dedicated post. I mean, it's not new money, we didn't get new money to create it. We've basically taken the hours off the case work, client work to be doing this kind of work. And I think it's paid off because it does positively benefit service users as well."* *(Learning disability team leader)*

*". . . it's interesting given that in [this borough] we spend in excess of nineteen million pounds on learning disability services across the whole economy. [But] we may as well be invisible in some quarters. You know, and.. you know, GPs particularly who sit on the forum of the PCT when they are delivered papers around learning disability strategy, commissioning strategy, out of area cost, are staggered at the amount of investment in learning disabilities."*

*(Learning disability team manager)*

*"[This borough has] got a significant investment in specialism in learning difficulties within the health economy, you know, a dedicated learning disability team, . . . so on one level I can accept that [we are well resourced]. However, you know, it's worth saying that . . . given some of the financial constraints that as a budget holder are applied to you, as they are other managers, you know, and that whole 'living within your means business' that is now far more part of a.. a primary care trust business than maybe it has been previously. . . . I try to be fair and equitable to all the professions, and I can be everybody's grim reaper. You know, I don't like to single anyone out particularly. . . .I guess we've just always valued it as a.. as an intervention."* (Learning disability team manager)

*"... there are drivers, you know, Valuing People says, you know, 'All people will have a health action plan', and we can only do that diaried in nurses' work as part of the work, and that won't hit the target. So if you want to hit it you have to make some investment, and you have to re-jig your priorities and you have to re-jig your resources. . . . it's not a long term commitment, but it's not a short term commitment either. You know, I'm happy to re-evaluate it and do what we have, you know, what we have to do."* (Learning disability team manager)

The resource commitment by the JLDT therefore is significant and if found from existing resources by prioritising the programme over other work. However the manager judges this to be necessary to try to ensure patients with learning disabilities' health needs are met. and to meet obligations in the Valuing People white paper both to facilitate access to healthcare and provide health action plans.

### **3.2.4 Impact of health check programme**

#### ***Practices***

None of the practice managers or nurses interviewed felt that the programme had had an adverse effect on the practice. Two practice managers commented that they were made well aware of what the commitment was going to be before the programme was put in place and so were happy that expectations were met.

The doctor responsible for initiating health checks in his own practice commented that he felt the programme increased the services his practice could offer. He felt it had also highlighted

issues within the practice, particularly in relation to consent and confidentiality. This practice had been offering health checks for eight years and staff commented that procedures had evolved over time.

*"As the years have gone on, I think everybody's probably got a bit more organised. And you know, now ... when we first did it, I don't even think the learning disability team knew where to refer people for eye tests, whereas now it's the same and we're all organised, and doing things like this. Dental problems."*

*(Practice nurse 6a)*

Practice staff commented that they felt the initiative helped them to tackle health inequalities and that running the clinics had made the practice more aware of the circumstances of their patients with learning disabilities.

*"I think no matter whether a patient's got any extra needs or a disability or any extra support they might need, they're still entitled to the same care no matter who you are . . . . I hope nobody would think, well just because they've got learning disabilities it's extra work for the practice I would hate the thought of anybody thinking that."*

*(Practice manager 2)*

The programme was not a top priority with any of the practices, however six practice managers and nurses felt that it was important enough to keep the clinics running. Only one practice manager felt that the clinics had low priority and this was because the number of patients involved was so small.

*"It is an important service. It's not one of our highest priorities, because we have other huge target groups, like.. and we have a big group of diabetics, a big group of asthmatics and COPDs, we have obviously drug misusers and alcohol misusers, and those, because of the area, and there's more patients in that group, those are our priority areas. But every patient that has a need is a priority. "*

*(Practice Manager 3)*

For another practice the clinics had become routine and embedded within practice services.

*". . . the support was there from when it was, came up as, as a concept and I think very much we felt we should implement it and see to it, improve the quality of life and then we were constantly reviewing it, you know, with our clinical meetings, so it was very much a part of what we think we should be doing and, we don't put posters up to say we do this, it's just part of what we do."*

*(Practice manager 7)*

In comparison with other patient groups therefore patients with learning disabilities appear insubstantial. However practice staff views appear to be that minorities needs should not be overlooked, despite the high demands placed on the practice for other quarters.

### ***Impact on Nursing Staff***

Practice staff were asked about the impact running health check clinics had on them. Eight practice nurses commented that they had gained knowledge of the services that the joint learning disability team could offer. In addition two practice nurses felt that they had gained knowledge about the medical conditions that have a particular impact on people with learning disabilities.

*"I suppose, you pass, you pass on the knowledge that this, this service is now available when people have come in to talk".* (Practice nurse 2a)

*"Certainly knowledge-wise I've got more information and more knowledge now you know of ongoing medical conditions that I might not be aware of. It's made me go and look up and see if what we're providing is, you know, appropriate. And I've had more contact certainly with the learning disability team. And I've got more awareness of all the services that are available at the moment."* (Practice nurse 7)

Four practice managers and two nurses said they were more aware of their patients with learning disabilities.

*"It's just giving you an extra way of looking at everybody, isn't it? If anybody comes in, a new patient with learning disabilities, then it just highlights you to may be let the team know and think of the whole aspect of it."* (Practice nurse 5)

*"I think it's probably just raised a bit more awareness. You know, I think, you know, we are a practice that are aware of patients with difficulties, and we always take into account, because we, you know, we're in that type of area."* (Practice manager 3)

In addition five practice nurses felt that the experience had improved their communication skills for dealing with these patients. Five nurses also felt that running the health checks had developed their interpersonal skills and confidence in working with this client group.

*"Communication is a big problem. You've got to be able to communicate. . . And be able to do it in the right way. And there's still, I still sort of think about this patronising*

*and saying I don't want to be like that. I want to try and ... because you don't know what that person understands a lot of the time.*" (Practice nurse 6a)

*"I didn't have any real issues with communication, I can, I've always been able to communicate with them but obviously they can't always use ... the more higher levels of medical terms, have to make it simple."* (Practice nurse 3)

*"You do try and be patient and explain and go through it all and take it very slowly, you know. That's the thing I feel, just taking things a bit more slowly and having a bit more patience really, instead of trying to rush people, which we tend to do, we tend to rush people."* (Practice nurse 8)

*"I think possibly the patients that come in that are terrified of a procedure, I think where you need interpersonal skills to try and persuade them, I think, yeah, yeah working with the Learning Disabilities does help that."* (Practice nurse 2b)

Two practice managers and one practice nurse described the atmosphere in the practice having a 'positive buzz' during health check clinics. Two nurses commented specifically on the satisfaction or enjoyment they had doing them.

*"Yes. And so, I think there was definitely a feeling that we were doing something right, . . . . we had very, such a very good turnout, but it was just the whole general, people being so happy to be here feeling that it gave us. Yes, I do. I remember that as a very positive buzz."* (Practice manager 6)

*"[The practice nurse] felt that it had been useful and she'd picked up a number of issues, so it had a positive feel to it at the end of it all."* (Practice manager 7)

*". . . . it's quite nice, you get this little buzz when you've picked up something that, you know, nobody else had done and I think it's also with the, [learning disability nurse] who was sat with me, she's, you learn what else goes on outside and what actually her role, cos obviously you're chatting in between but what her role is within the, within the team and it was nice."* (Practice nurse 10)

Practice nurses described that they and the learning disabilities nurse each had a clearly defined input had to the whole process. On the part of the practice nurses the clinical skills involved were described as 'normal', but employed as part of a team working to meet the health needs of their patients with learning disabilities.

*" . . . there was more input than a normal health check because [the learning disability nurse] was there but my input was exactly the same as what it was on a normal health check. . . . [the learning disabilities nurse] can put them into services such as social workers, any incontinence nurse, anything like that, she can put them into the right spot. I think that's, I think that was a good reason that [she] was there."* (Practice nurse 10)

*"I think it's very good. It's very good to have a link with a nurse from the learning disability team, who can provide extra information and knowledge, you know, that you might not particularly have access to."* (Practice nurse 7)

From their point of view learning disabilities nurses felt that they had also learned something of the demands on practice nurses and having successfully implemented health check clinics in several practices felt an increased confidence about approaching others.

*" . . . it's good to have some, a perspective of other people's pressures. Because it's easy to sort of say "People don't do this and they don't do that" without really understanding where their pressures already lie and without also maybe thinking a bit more about the sort of help and support that they need to actually be able to do that."* (Learning disability nurse 1)

*" . . . certainly people have got a new appreciation of what, how primary care works, the mechanics of primary care, the pressure that primary care is under, the resources that primary care can offer. And so people, I think nurses are more confident about knowing who to approach and what can be offered. . . . "* (Learning disabilities team leader)

Several practice staff appeared to feel that running health check clinics for people with learning disabilities was a positive experience. Although the clinical skills involved were the same as for other well-person checks, team working with learning disability nurses gave them knowledge of the range of services available to patients with learning disabilities and for some raised their awareness of these patients within the practice such that they felt more sensitive to their needs and more likely to alert the learning disability service when new patients registered. For their part learning disability nurses gained a greater awareness of the working practices within general practice and were able to adjust their own practice to accommodate to the general practice demands.

### ***Impact on patients***

The timing of offered appointments was convenient for all the service users and carers interviewed. One person was in full time employment, however his parent stated that his

employers were happy to let him take time off for these appointments. Another carer expressed the opinion that she would have been able to change the appointment if it were inconvenient. Two of the service users showed an awareness of the invitation. One said that the invitation had come from the practice and the other that it was from the learning disability team. No one reported difficulties with transport to the practice. All had cars available to them if necessary.

*"They gave me a time, and er. I think the thing, er if not, if I did not, couldn't make it I would phone them. I am sure they would give me something else, but it was quite convenient for me and for the ladies and so I didn't have need to change or anything. I didn't have any pressure or anything."* (Carer 203)

In the four households where service users were supported by paid carers only one reported staffing levels high enough to cope with attendance at health appointment in any circumstances. In another difficulties were encountered if they needed to take a particular resident to an appointment because she needed two carers to support her. This carer stated it was often easier to take all three residents to the appointment in these circumstances. Another household experienced difficulties if two residents had appointments at the same time but at different healthcare settings. The adult placement carer regularly took both women she supported to each other's health appointments.

*" . . . it can be difficult with the staffing as well, if you're taking, if you need two people to go out with somebody. More often than not we do get a third person and we can work round it but sometimes we can't."* (Carer 103)

*" I take them together and then it was first one and then it was, but that time they had both together, because it was a very big, very very big room. So, its not that difficult job and staff is very very good."* (Carer 203)

### **Communication**

Carers reported that five of the patients with learning disabilities answered health questions on their own behalf. In the remaining case, although the person could speak for herself, she needed extensive prompting. Three carers commented that they only intervened occasionally when the person was unable to answer, or to provide details of past history. Carers commented that the nurses explained what they were going to do if they needed to conduct physical checks such as blood pressure. Three of the service users confirmed that they spoke to the nurses who asked them 'How're you going on?' However, service users commented

individually that they weren't sure what the physical checks were for, couldn't follow all the questions, or spoke on their own behalf only occasionally.

*"Interviewer: Who did most of the listening at the health checks, do you think?"*

*Service User: Me.*

*Interviewer: You were listening.*

*Service User: I were listening. N (carer) talkin' Didn't you N?" (Service User 203)*

*"Service User: They, they talked to me every time, yeah.*

*Interviewer: They talked to you every time, that's good. OK, so who talks the most at the health check?"*

*Service User: Probably me . . . 'cos I 'ave to explain to 'em what I . . . I 'ave to 'ave it done in me chair." (Service User 201)*

*"Interviewer: Do you know what the nurses found out at the health check?"*

*Service User: Don't get that far.*

*Interviewer: You don't get that far? Yeah, so while you were there what did they do. They, did they ask you some questions?"*

*Service User: Erm. Yes, some questions that I can't follow!*

*Interviewer: You can't follow?"*

*Service User: No. 'Cos, 'cos the . . they speak at yer, not to yer!" (Service User 201)*

*"Interviewer: Who talked most at the health check?"*

*Service User: Nur, nurses.*

*Interviewer: The nurses. Did you talk?"*

*Service User: Occ, occasionally.*

*Interviewer: Occasionally. Who listened most?"*

*Service User: The, nur, nurses that were tellin' us, an' listenin'." (Service User 202)*

*"I must admit, the nurses always say, "Speak to [your son] first," and they know him by name, and they call him by name. They ask how he is and how he's feeling today and all that, that is lovely, that's what I expect." (Carer 201)*

### **Physical checks**

Three carers recalled the person they supported having their blood pressure and weight checked, two recalled checks on diet, dental health, sight tests and providing a blood sample for testing. Individuals recalled checks on height (BMI), exercise, medicine review, chest and one person received an injection. One carer did not recall any physical tests during the check.



This was a person with a mild learning disabilities whose needs centred around mental health. None of these checks were problematic for the patients involved.

Four practice managers and three practice nurses agreed that one of the major benefits of the health check appointment for patients with learning disabilities was 'time'. The half hour appointments meant that the clinic had a calmer feel in some practices than a routine clinic. It took a holistic approach to patient need and offered a valuable opportunity for patients and their carers to talk through their concerns.

*"They've got a dedicated time. If they were to come in in regular consultations they wouldn't have the time to go through every.. every issue with the patient.... which obviously the patient benefits in they're not missing out on any services we can, you know, we can offer. So it's the time factor really, if, we've got dedicated time."*

*(Practice manager 2)*

*"I mean obvious things like the ability to give people time to, you know, to bring up their problems. And so that they can, to think about what they want to say and to address those needs. We certainly you know, your interpersonal skills do play a part in the time that's available. . . .to be able to offer a 30-minute appointment is good for this client group."*

*(Practice nurse 7)*

The doctor who initiated the first health check clinics and a manager at a different practice felt that a particular benefit for patients in offering health checks was access to a structured check. This type of check is less likely than those conducted opportunistically, which tend to be time limited, to overlook health issues.

*". . . there were certainly quite a lot of people who didn't, who didn't access especially preventative services. And so it didn't work very well on an ad hoc opportunistic basis. Some groups of patients it seems to, you know, opportunistic screening works quite well. . . . So I think probably if you're going to offer a good service, you probably need to have some structure to it."*

*(General practitioner)*

*"I think the benefits are that you can actually set your parameters and criteria beforehand and what you're going to check, so you know, you know, that these are the key things you're looking at and you can then make sure you pick up each item because you go into a structured thing, . . . . Whereas when you do opportunistically I think you tend to be responding to perhaps an acute illness and not necessarily other things, or have the time for things, it can be difficult."*

*(Practice manager 7)*

### **Other benefits**

Several health professionals commented that health checks enabled the practice to keep in touch with patients who attended the practice infrequently. This was seen as a particularly important form of support for people with mild learning disabilities who may have little support from statutory services, to ensure their health needs are met.

*"I think one of the difficulties is, . . . . that people [with mild learning disabilities] aren't always very good at keeping appointments and because of that, they tend not to get recalled. And so they do end up missing out on services really."*

*(Learning disabilities nurse 1)*

*"The mild ones didn't turn up. The ones who probably haven't got it now, you know, it was on the read code."*

*(Practice nurse 7)*

*". . . . people do fall through the net, like one bloke who had heart problems, missed out on his out patient appointment quite a long time, maybe up to a year. And we managed to get him another one, you know. If he hadn't come for a health check, I don't know when anybody would have realised that he hadn't been, you know."*

*(Practice nurse 6a)*

There were some concerns however around identifying people as having a learning disability at all. Nurses were concerned not to 'label' patients as learning disabled unnecessarily and therefore found it difficult to deal with questions on why individual's had been invited to the health check clinic.

*"I found it a little bit difficult really, cos some of the patients have said "What is this check for" you know, say "Well it's just to get you to come into the surgery a little bit more and see that everything's ok, you know." "But why, why do you want to see me and not, me neighbour next door who's your patient?" you know, there were some that were a bit, it was a bit like treading on eggshells with some of them. The pa', some of the elderly parents were a little bit prickly about things as well. Just defensive I suppose."*

*(Practice nurse 6b)*

One can only speculate on why parents might feel defensive. It is arguable that they may see an invitation to their son or daughter to attend a health check as a slur on their ability to adequately care for them as they themselves reach old age. This was not amongst the

objectives of the health check, however one practice nurse felt that there was a role for health checks in providing an early warning system against abuse.

*"I mean there's this nasty little word as well isn't there? And sometimes it's like, shall we say it gives you an insight, to make sure that somebody's not being abused or anything like that doing a yearly screen."* (Practice nurse 10)

The ongoing nature of the clinics, with repeat visits nominally every other year, allowed the nurses to build up relationships of trust with patients with learning disabilities and appeared to provide them with reassurance about using their general practice. One practice manager and four practice nurses felt that the clinic provided a positive health care experience for these patients. It gave them a sense that there were people interested in their well-being.

*"I think they just feel as though, they're glad that someone's taking an interest in them. I think. We have, we have identified a lot of health needs, you know, thyroid problems and a lot of them are o', obese and you know, it's just, I think, I think it's done them a power of good really. And they're a lot more willing to come and have a chat or come and see the doctors than they used to be."* (Practice nurse 6b)

*". . . it's surprising if you don't see ... the impressions you (..) get if you don't come in. So first of all I would say it's contact rather. And knowing that it's not a scary place or ... you don't have to be ill to come, they can just come and just see us, make sure everything's fine."* (Practice manager 8)

There was some agreement that the clinics raised service awareness for patients with learning disabilities and their carers. Two learning disabilities nurses commented that the clinics also helped service users to become more aware of their own health issues.

*". . . you can keep them informed of anything else that's going on, or anything that's ... how the system works, if they need to do something, see someone, you know, that that's available."* (Practice manager 8)

*"It's not just about finding ill health as much as healthy living, about good diet and exercise and all the remit that goes with that. And advising carers about, like, their weight. Cos weight management's a big issue with everyone, never mind people with learning disabilities. And just advising them, where they could actually go to get a bit of exercise. Like healthy eating groups that kind of thing, which I don't think they would get if they're left to their own devices."* (Learning disabilities nurse 2)

Nurses were asked specifically about providing health checks to patients with learning disabilities from minority ethnic backgrounds. However few mentioned having seen patients from these backgrounds at all and those that were seen were from families where there were no problems communicating in the English language. The learning disabilities team leader was concerned that more people from minority ethnic backgrounds had not been seen.

*"[People from] minorities may have specific health needs as well. So I think we need to be even more proactive about ensuring that people from ethnic minorities do access health screening programmes. And I don't think that's happening as much as it ought to be. I think it's an area we need to be working on even more. . . . . You know, I do wonder whether, when people say "There aren't any problems" and "There aren't any difficulties" whether it's because they're not seeing people?"*

*(Learning disabilities team leader)*

Four of the carers recalled that there were concerns around the person's weight and the need to be careful about eating habits. Two were advised that the person needed to exercise more, however in both cases the carers had difficulty identifying suitable activities for the individuals concerned. Two carers reported that they were given reminders about taking medication regularly and one carer reported that they were asked to ensure that the person they supported attended hearing, dental and optical health appointments.

Two service users recalled being advised to lose weight. One had tried exercise but did not feel that it had helped so was going on a diet. The second had tried a range of exercise activities but soon lost interest, she was also being careful with her diet. Two people also recalled being told that they needed to be careful of their blood pressure. One stated she was advised not to rush, the other said he had to attend for regular checks.

*"I'm goin' to stop eatin' chocolate now. The nurse said, at the doctor's the other day, I've got to stop eatin' chocolate and crisps and biscuits."*

*(Service User 203)*

*"Service User: Nearly fourteen stone. I'm gonna loose it.*

*Interviewer: Your going to loose it?*

*Service User: I'm too 'eavy, I say what, what can I do loose it?*

*Interviewer: What did they say you should do?*

*Service User: Yer can't do nowt. Yer can't do nowt to have it ??? when you want loose it. . . . I've even, I've even gon't bloomin done exercises. That'll make no difference. . . . I'm havin' to do, I'm goin' do everythin', everythin t'see if I can loose it.*

*Interviewer: Yes. So you've been trying.*

*Service User: Arh. But, but I've bin puttin' more on all like t' time. . . . I'm goin' on a diet now."*

*(Service User 101)*

*"Interviewer: Your Mum was telling me you know all about healthy diets.*

*Service User: Well, some of it*

*Interviewer: Some of it.*

*Service User: I don't understand 'alf of it.*

*Interviewer: What have they told you about healthy diets?*

*Service User: You 'ave to take some of your weight off."*

*(Service User 201)*

*"... one of the staff got her to join [a gym]. She went to see it first and then she joined it. She went a few times, but she enjoyed the café more in there. And she's been to the gym with the day centre and she doesn't like it. She doesn't like the machines and things. She'll say "It gets my blood pressure up, on them machines." So, and she's been to Slimming World and she loses interest fast. She doesn't like going. And you just can't get her to go. It's pointless, you know. She just doesn't enjoy it."*

*(Carer 102)*

Five of the carers reported receiving a Health Action Plan after the person's last health check. However one of these felt that it was in an inappropriate format as the person she supported is partially sighted and unable to read printed text. She suggested a tape format would be more suitable. Other carers commented that the booklets were useful reminders, however it was unclear to what extent three of the service users could use the booklet. Even with supporting pictograms it was difficult for one patient with learning disabilities to understand its content without significant carer support.

*"Well that blue book [Health Action Plan] is the latest development, that's the only.. because before that we did.. we got. I've forgotten what we got, I think we got a letter to say, you know, that the health check had been completed and all this, and if we had any problems to get in touch with our doctor, which we would have done anyway. And that was about all. But that was the first time we got something to take back home with us. . . . For [my son], it would have.. I would have said if they'd put it on a tape, a tape-recorded.. broken it up into segments, short sentences, short segments, a pause, . . . That would have made an impact."*

*(Carer 201)*

*" Well, the thing is too, there's no monitoring with this. I mean yes,he has... he attends [the] dental department every six months. How do they know? I mean actually he's attending once a month at the moment, but there's no.. nobody's contacted me to see... glasses checked*

*regular. That's up to me. How do they know that I've checked them regularly or not?"*

*(Carer 201)*

Carers felt that general practice was the right setting for these clinics because the staff there were either likely to know them already or the setting was familiar to the person being supported. One carer also felt that attending for health checks helped the person get used to using their local health centre. Two carers specifically commented that the experience was reassuring or enjoyable for the person they were supporting to have attention paid to their well-being.

*"Interviewer: Where do you like going best for your health checks?"*

*Service User: 'Ere.*

*Interviewer: Just here. The health centre or . .*

*Service User: Yeah, 'ere. 'Cos I . . . you spend all yer time waitin' in outpatients."*

*(Service User 201)*

*"I think it, it get, well for all of them, I think it gets them used to ... to going and it, it, it, there's no fear then of going. I know [this person] hasn't, but some of the residents are a bit (...), you know, but if they go regularly and have these checks they're fine."*

*(Carer 102)*

Service users also had positive views of their experience. Four of the six commented that the purpose of having health checks was so that they would not get ill, or would get better. They made a range of comments about their experience suggesting that their relationships with the nurses were good. The only negative comments were about the premises. In particular that some treatment rooms were very small which proved a particular problem for a man in a wheelchair. This man felt that communication with practice and learning disabilities nurses was good, though he could not understand all the questions. However communication with receptionists could be improved if it could be arranged so that they spoke to him face to face, rather than to the top of his head. One woman commented that clinics could be made better if the room could be tidier. Although superficially this might appear a unimportant matter it may have relevance to the success of the person's health check. Attending to relevant information can be difficult for people with learning disabilities while there are competing stimuli vying for their attention. A 'tidy room' therefore would provide fewer distractions and allow the person to attend more fully to the issues being addressed by the nurses.

*"Interviewer: Was there anything about the nurses doing the checks, that you would change if you could, or anything they did?"*

*Service User: No, quite pleasant."*

*(Service User 202)*

*"Service User: I'd go again N (carer).*

*Carer: Yeah, it's good for your health.*

*Service User: Its good for me. I can go for well check again? . . . They want me to come. I want to come again, em, [Interviewer]. When we get a letter, [Interviewer], yeah."*

*(Service User 203)*

*"Interviewer: What do you like about going?*

*Service User: What to the doctors? They looked after yer.*

*Interviewer: You like it. You feel you're being looked after?*

*Service User: Yeah."*

*(Service User 102)*

*"Interviewer: Is there anything you don't like?*

*Service User: Er yeah, bein' told off.*

*Interviewer: Being told off? Yeah? You think you might get told off at your health check?*

*Service User: I don't, I don't get told off but, if me blood goes any 'igher!*

*Interviewer: Yes, you've not been told off yet.*

*Service User: Nah.*

*Interviewer: Your a bit worried you might.*

*Service User: Yeap.*

*Interviewer: Yes. How can we make going for a health check better than it is now? What would you tell those nurses?*

*Service User: 'Bout explainin' to people a bit more."*

*(Service User 201)*

Health checks were perceived as appropriate for people with all levels of learning disability. For people with mild learning disabilities, who may have limited or no contact with services on a regular basis, health checks were seen as a useful link both to ensure relevant health appointments were being kept and to the wider range of services (specialist and mainstream) should these become necessary. Increasing severity of learning disability is associated with increasing difficulties in recognition of signs and symptoms of ill health, and the means to communicate health need. The health check for these individuals was seen as an opportunity to spend time investigating common health issues for people with learning disabilities in an ongoing way that builds relationships and trust in their general practice.

#### *4.4 Impact on Carers*

Four carers commented that one of their main roles during the check was to help explain procedures to the service user. They described having to reword questions so that the person could answer them, as well as clarify service user's answers for the nurses. Two carers stated that they also acted to reassure or provide moral support to the person they supported throughout the process. Four of the carers commented that they answered questions on behalf of the person they supported. One carer had to provide physical assistance due to the significant physical disabilities of the service user. She also acted as an intermediary to provide information about his mental health needs in relation to accessing healthcare services.

Three service users commented that their carers helped them 'fill out their prescription', were there to 'help if they got worked up' and 'helped them if they got stuck' trying to answer a question.

Learning disability and practice nurses appreciated the extent to which carers enabled the health check process to happen. Their key roles in escort, transport and support to the person with learning disabilities was described as vital for this group of patients. By the same token there were occasions when people living in residential care did not attend health check appointments because their support staff did not make the arrangements to bring them.

*"I mean I suppose for some people, there's the pressure of actually getting to the appointment and supporting that, you know, making the time to do that."*

*(Learning disability nurse 1)*

*"some carers find it difficult, you know, if it's a time when they would go to the centre or something, and they don't want to take them out of that time, and transporting them is a problem and things. Sometimes whilst they're in with the doctor it is easier just to see them. . . . . "*

*(Practice nurse 8)*

*"[They] can be useful to provide background, and certainly when the carers are there, [the people with learning disabilities] very often feel more comfortable. . . . I think they're quite important, cos they encourage attendance and they, they've got their own knowledge of the services that are involved and the personnel, so they're certainly an important part."*

*(Practice nurse 7)*

*". . . a couple of times people didn't come for health checks because there weren't, wasn't anybody there to cover anybody else that was left in that house. And whether there is enough people on the ground, I don't know."*

*(Practice nurse 6a)*



The nurses felt that the health check appointments gave carers an opportunity to talk through their concerns no matter how trivial they may seem and discuss problems with service receipt. One practice manager felt that it was a valuable opportunity to 'touch base' with carers and discover their needs in relation to their caring role.

*" . . . maybe the carer would feel that perhaps they've had more time to go through things, perhaps things, little things, maybe more trivial things that they sometimes think they don't wanna bother the doctor with. I would think they'd have time to kinda perhaps come out with more of those worries."* (Practice manager 7)

*" . . . carers of patients with learning disability are a particularly important group, and these clinics, it's an opportunity to, to touch base with them as well and see if they have any needs as well. And particularly to ensure that they are in touch with the Learning Disabilities Centre so, so that they know where to go for their needs."* (Practice manager 10)

*"Sometimes the littlest thing can cause such problems. You know sometimes, last week we had a guy and [the carer had] gone almost demented because she wanted a blue badge for the car, the disabled sticker. Didn't know where to get it. . . . You know, it was something and nothing. . . . But that was causing her major problems. So at least, (...) didn't do much for her in the health check. But at least he got a new sticker."*

*(Learning disability nurse 2)*

Several carers were described as enthusiastic about the experience and it was suggested that interaction with nurses may have made carers feel 'part of the team' emphasising their health role. However not all attitudes towards the process were positive. The nurses came into contact with parents and paid carers who were suspicious about the motives behind health checks. There were particular concerns about ageing parents who, the nurses suggested, may have had worries that the health check was the first step in removing their son or daughter into statutory care.

*"There was, some of the patients, one or two of the patients that I saw, sometimes it's clear that perhaps the carer, the parent, didn't want interference at all . . ."*

*(Practice nurse 4)*

*" . . . like I say, there was an old lady who says "there's nothing wrong with her so she's not coming"".*

*(Practice nurse 5)*

*"Some of the parents were, were a bit frosty, that was the . . . because they didn't really want anybody to become involved in things. That's, probably, I found that a little bit hard. . . They were a little bit curious about the learning disability nurse, you know, they wanted to know where they came from and what did they want this information for and, they were very suspicious really."* (Practice nurse 6b)

Difficulties were also experienced when paid carers who were unfamiliar with the person with learning disabilities supported them at their health check.

The nurses commented that an important outcome of the health check for carers was that they were able to make carers aware of learning disability and practice services that were available as well as provide health advice and education particularly around diet and exercise. Often this advice would impact directly on the type of health follow-up required by the person with learning disabilities, the success of which, along with recommendations to access other primary care services such as dentistry and ophthalmology, relied on carers' co-operation for their success.

*"I think, I mean, [the learning disabilities nurse] asked a few more questions to what I'd asked about, incontinence and so forth, so we were able to give advice to the carer, they would ask questions and we were able to give advice to them then, how to care for these people, yeah."* (Practice nurse 2b)

*". . . we're so dependent on the carers for the follow-up, cos all the, most of the recommendations, and we write it, and who's responsible for it, you know. Like, you know, even talking about a simple thing like weight management, they're the ones who are responsible, take them for a walk."* (Learning disabilities nurse 2)

The checks were also felt to provide support to carers to reassure them about the physical well-being of the person they care for and provide practical help or guidance.

*"I think it's impacted on the carers as we said, because they're, you know, they have developed a relationship with me, so they're perhaps also willing to attend for health screening or if they've got any chronic conditions."* (Practice nurse 7)

*"I think they find it useful, or reassuring that they've not got anything. Because often they're quite healthy, the learning disability, you know, their blood pressures and everything weren't too bad at all, they were quite good. So I think they're just reassured that there isn't anything major."* (Practice nurse 8)

Carers interviewed were positive about health checks. Three carers stated that the health checks were reassuring for themselves particularly in relation to an older man whose health needs have increased as he got older. Another commented that findings at health checks sometimes provided an explanation for associated behaviour that they had previously been concerned about. It was also felt that this focus on health checks made the service user more aware of health issues.

*"It's not stressful by any means, no. It can be helpful because, you know, you can find out if there's something wrong and that problem can be sometime the answer to another problem that you're having at the time. . . . . "That's why she's been really misbehaving," or, "That might be why she's not been feeling so well in the mornings," or, you know, things like that. It can be the answer to other problems that you've been having, it can be very useful."* (Carer 103)

*"Definitely. Definitely. I mean it doesn't matter how old you are ... and just to keep, you know, health checks going and his eyes, ears, oh yeah. And he's ... it's to help [the person] as well in't it, you know. Cos as, as they do get older you, they do slow down don't they, you know."* (Carer 101)

Carers made specific comments on the luxury of time to talk things through and spend time explaining issues to the person with learning disabilities confirming health professionals' view. One carer, who had no other contact with services, was particularly keen to retain this service input. Five of the carers specifically commented that they felt health checks should be undertaken annually. The remaining carer made no specific comment but was a frequent attendee at the practice with the person she cared for for blood pressure monitoring and medication review.

*"I didn't find it stressful at all, no. I thought it was helpful, yeah, because it, it was interesting as well, yeah. Cos it was a new, a new ... thing that she was going for as well and I'm sure, and I'm, I'm hoping it'll be regular that she goes for them, it won't just be a one off, I hope it'll ... you know, perhaps even if it's just 12 monthly, you know. I think that would be good."* (Carer 102)

*"he's quite, he's, he enjoys I think almost talking to, or being made a fuss of by health professionals. And fortunately most of the ones that we've had dealings with are sympathetic to his problems. . . . They don't give you the brush off and make you think you're wasting their time or you know either "hurry up and get on and get out so I can get onto the next one." Right. They make allowances for you."* (Carer 202)

*"Well to me the most important thing is the continuity of contact. And the opportunity for someone, for somebody outside the family, if you like, to perhaps pick up on something that needs attention, and [my son] might not have recognised as requiring help, or none of us might recognise as requiring help. The thing that is lacking really from the social services broad spectrum and including the learning disability team and so forth, that there is no continuity of contact. It's "come and see us, get in touch with us if you need help". But if you don't know you need help, how do you go about it?"* (Carer 202)

*"I think it should be every year. To be more safe. Definitely because, I mean, situation could change in a night, overnight, I mean, [this person] only last one and a half, two and a half years, she was really really, I mean very very bad, and now she is getting better. I think it is, it should be once a year. . . . Two years is too much. Especially, not for people like [this person] 'cos she's in good health, but especially for people like [another person cared for who has ongoing health problems]."* (Carer 203)

*"I think that's, its very very important. I mean, er, health checks are import., if they're healthy, if they are healthy and they're happy its good for me. I won't get so stressed, "oh they are ill, they are this and that".. . . [after] their health check I have no worries, I know, I know they are good, they are in good health, and then I know what their blood test show, I know everything, blood sugar level, everything. So I'm quite happy."* (Carer 203)

As one would expect, carers were key to the operation of the health check clinics through their role in enabling people with more severe learning disabilities to attend their appointment and in providing information. In turn, however, the health checks were perceived as a support to carers by providing reassurance about the physical health of the person they cared for. However, several parents were considered by the nurses to be at least initially suspicious of the motives behind the health check and monitoring for signs of abuse and coping in the home environment were raised as perhaps a secondary role, or unintended consequence of health checks.

#### *4.5 Impact on other patients in the practice*

Six practice nurses and one manager discussed the impact of the health check programme on other patients in the practice. They agreed that there were no negative effects. Two nurses pointed out that if they had not been involved in the health check clinics for patients with learning disabilities they would have been conducting an 'open' surgery or doing home visits for elderly persons' screening or blood pressures.

*"Well we do all sorts of, it's likely there'd be an open surgery or I'd be doing a diabetic clinic. So yes, I would say our open surgery sort of miss a day because of that, but they're patients just the same, so for me it doesn't, doesn't make any difference."*

*(Practice nurse 10)*

*"[I'd] Just have to have a splurge at the end of it, think well ... And especially if somebody was in a nursing home and such like, you would think "Well they're in there, they're all right, they've got somebody who's looking after them" or whatever. And it isn't desperate so I'm not going to do it this week, I'll do this instead. Try to think well that's more important."*

*(Practice nurse 6a)*

Two practice nurses described employing communication skills they developed as a consequence of conducting health checks with people with learning disabilities, with other client groups.

*"I suppose patients with mental health problems [have benefited] . . . . Just how, how to actually talk to them, communicate with them."*

*(Practice nurse 3)*

*"I mean we have a lot of patients that aren't, haven't got learning difficulties but are definitely low in IQ, you know, . . . we have some patients that you, no matter what you (laughs) no matter how many times you, you tell, you know, things like contraception or they still come back and say "No, I don't understand." You know, so I suppose in a way it has helped me cos I, you know, I, it's a way of explaining more isn't it, more depth."*

*(Practice nurse 6b)*

Conducting health checks for people with learning disabilities did mean that other activities had to be cancelled or postponed, however the competing priorities were easy to rationalise in that patients with learning disabilities were as entitled to nursing attention as any other patient and that other patients would not suffer for missing a single visit or delayed appointment. In addition the experience of interacting with this patient group allowed some nurses to develop their interpersonal or communication skills which was of benefit when working with other patient groups.

### **3.2.5 Programme future**

#### ***Future of health check programme within participating practices***

The overwhelming opinion of practice staff was that they would like to continue with the programme. Some practices would be prepared to run these clinics even if support from the learning disability team was not available, however seven practice nurses felt that input from the team was an important part of the clinic.

*"She (. . .) asked the questions about social worker, about sexual health and without it sounding awful, sometimes you haven't got the time to do all the other little bits that's included in the health check. So I think [the learning disability nurse] plays a very, very important part in following up that, doing the programme for them and making sure that it's set in place."* (Practice nurse 10)

*"I would say that it is something that we still need to do together because they have their expertise and we have ours. I don't think it is something that we can, we can take over."* (Practice nurse 2a)

*"I think we'll continue with the recall probably 12 monthly and look at updating our register. Hopefully, I know the input from the learning disability team may stop, but I think that's quite advantageous if it can continue."* (Practice nurse 7)

One practice, which had seen an enormous increase in list size over the preceding two years including many patients from vulnerable groups, was considering whether they were able to continue with the programme.

*"I think we probably need to have a look at it again. We have let it sort of be put on the back burner because we've not had any more feedback from the learning disabilities team, . . . and the annual reviews have not come off as we initially thought. So we need to have a look at it, we need to see if we can implement it. . . . But it depends on the size of the group, and obviously because they're longer appointments, it's whether we can get them all in. We've got so many groups now that we do recall annually, it's whether we can get that done."* (Practice manager 3)

A practice manager and practice nurse, at different practices, felt that the programme was still in the 'trial' stage.

*"I think it's still in its experimental stage. I would [like to see it continue], but maybe we've got to do more work with it. . . [because of the number of people who did not attend at recent clinics] . . . Like I said before, we look at ourselves as a forward thinking practice, so nobody should be discriminated against. (...), you know, with groups of*

*patients so yes, this is one of the things that we've been made aware of and we want to continue."* (Practice manager 5)

*". . . actually communicating with the patients is not an issue. That's not the problem, it's ... having access to ... the services that are available was more of an issue. I don't really have feelings either way.[on whether the practice should continue with the programme] . . . I don't know, cos it depends what the learning disabilities team are willing to offer anyway."* (Practice nurse 3)

Only one participating practice had not completed a second round of clinics and this was due to lack of nurse hours in a small practice.

*"The reason was lack of nursing hours and basically that's it. . . The time restraints, and it was time of huge change at the practice."* (Practice nurse 4)

At another practice the nurses speculated that patients with learning disabilities might be able to access their generic 'well-person' clinic after their initial health check conducted in association with the learning disability nurse.

*". . . I would say perhaps for these patients having problems sort of walking or whatever coming in, we need half an hour, just for, just to give time for disability but to come into a normal clinic, not a specialised clinic after that initial, you know, after that initial interview."* (Practice nurse 2a)

*"I think hopefully we'll be able to send out for them when they're next due a health check. Whether they'll be in specific clinics for learning, or just brought into general clinics."* (Practice nurse 2b)

The practices were therefore positive about continuing the programme. There was significant support for continuing the clinics as a joint practice and learning disability nurse led programme, each bringing their own strengths to the clinic. However there were other models proposed including moving to generic well-person appointments with the practice nurse after an initial practice/learning disability health check.

### ***Future of health check programme roll out across PCT***

When asked about rolling out the health check programme to other practices participants agreed that the main obstacle would be perceived as lack of nursing hours.

*"I don't think the practice managers themselves would be. I think if there was any resistance, it would probably come from either the doctors or the nurses because they're the people who actually have to do the clinics. And they're already pressed for time. It, as much as everybody would like to do all the things that are good for the patients, we're all busy people and sometimes choices have to be made, if, if they feel overwhelmed with the patient demand for other things, then they don't like to take on things that aren't essential."*

*(Practice manager 10)*

The practice manager of a large practice speculated that small practices might have difficulty trying to implement this type of programme.

*"You see if you're a small practice and you've only got part time, you know, that is a big cost. Perhaps people don't understand really what, (...) cost what do we mean but if you think of that time, that nurse then can't be doing other services."* *(Practice manager 7)*

Staff from two other practices felt that the demands on large practices would be considerable.

*"Maybe it's a time constraint, I don't know, that might be one of the barriers (...) they were allocated double the normal length of time appointments than, than. . . ., whether for a practice that has got a lot of this group of patients, whether that, you know, time.. I don't know."*

*(Practice nurse 2b)*

*"Deciding who the patients are. I mean I'd worked here a while so I, and so have the doctors, so we did know quite a few of ours. If you were new to the practice and it was a very large practice, you might struggle more."*

*(Practice nurse 8)*

*"Time. (Pause) Knowing who, who to send for. ... And actually getting the patients to come in, whether it may be a single handed practice or it's ... time's a big factor. And other priorities that the, within the service cos obviously the GP contract does actually have a big impact on the services that you offer."*

*(Practice nurse 3)*

*". . . if it was a practice that obviously there was a single Practice Nurse there's and there's no support from it other than, you know, . . . .and I think it might be difficult obviously with everything that's, you know, being bombarded towards us now regarding GP contracts and things like that, em and obviously depending on which area they're working, you know, there could be a much higher population of people with those needs . . . . em so I think it could be a staffing resource issue."*

*(Practice nurse 9)*



Several practice nurses and managers felt that it would be useful to offer practices financial incentives to implement the initial health check clinics, perhaps as part of the GMS contract or NSF directives.

*"Well one of the things is, it's not part of the NS, there's no NSF for learning disabilities, now if there was then it would be done. Or if there was some cash incentive, it sounds awful, . . . but that's what I think. I think that would help ... if maybe ... you know, maybe in, with this new contract, if they made it part of an incentive scheme, that's one way (...)."*

(Practice nurse 6a)

Resources for the learning disability team were also considered a factor in the feasibility of rolling out the programme across the PCT.

*"Whether the resources are there. I don't think you can do it on a part-time (...) which is what we've got at the moment. I think we're making a good stab at it but ... Whether or not it's realistic to think that we can get all the practices on board with it, with the resources we've got ..."*

(Learning disability nurse 1)

One way to conserve practice and learning disability team resources was considered to be to use the learning disability service to initiate health check programmes but then for the practices to take the lead on setting up and running future programmes as suggested by some practice nurses above. In this model they would only call on the learning disability team to attend if a patient had particular needs that required the specialist skills of the learning disability nurse.

*"So I think long term, it's about working ourselves out of a job, that we skill people up, practice nurses are more aware of services and this client group. So that might be one way in which we would be able to work with all the practices, some have done it three, four times. We can say "Oh we'll send a nursing assistant" or something. Or "We'll be in touch with you when you're doing it - just let us know if you need us to come to any particular appointments" but slowly withdraw I think."*

(Learning disability team leader)

*"I would see them then taking on the, taking on the role. I don't think practices that have done it two or three times.. need someone from [our service]. They now know where we are, they know what services we've got . . ."*

(Learning disability nurse 2)

*". . . I think it would be quite useful for us to maybe look at what the practices actually feel they need to take things forward. And it might be that we produce, I don't know, some sort of*

*in service directory of, you know "These are the services that you can refer onto for people. These are the groups that we run, you know and a contact person." I'm not sure how much information we actually give people to be able to access us really."*

*(Learning disability nurse 1)*

In the longer term the learning disability team leader and manager felt that it may be possible to use 'Assistant Practitioners' to substitute for practice and/or learning disability nurses. This new role is currently under development in some general practices in the PCT.

*"But we have new opportunities now, because we have in [the area] a programme called Trainee Assistant Practitioners. And the Trainee Assistant Practitioners are generic workers who have had two year training period, working across the disciplines. So the idea is that you pick up skills and responsibilities from OTs, physios, nurses and in our case social workers as well. And eventually they become Assistant Practitioners. They will be a discipline in their own right. . . . and we've just arranged a programme with a practice, a large practice who want their Trainee Assistant Practitioner to run the programme with our learning disability nurse. So that's an interesting way forward."*

*(Learning disability team leader)*

*". . . the practices are signing up to the trainee assistant practitioner programme, and are sending healthcare assistants and practice nurse assistants maybe onto the TAPS course, and are developing them to do health screening. So that is one way of taking some of the pressure off practice nurses, but an assistant practitioner could adequately be skilled to be the person that does the health check with us in primary care. I'm a little bit concerned that maybe it's a little bit further dilution away from the GP, but it is, you know, it is an appropriate network, it still is in primary care."*

*(Learning disability team manager)*

In the meantime however the team intend to use whatever contacts and resources they have to roll the programme forward.

*"It is our intention that every practice will do.. have a screening, and every practice eventually will see it as their responsibility to do the recall, and we'll continue to invest in making that happen to that point, and then sustaining it, but in the hope that they will take some responsibility. And I think some practices will be happier to do that sooner rather than later. Some might need that longer than others, you know"*

*(Learning disability team manager)*

*". . . what we're doing now more is using those contacts we've got through the good health sub-group, the commissioner and the clinical governance lead. Who meet these people every day, to say "Can you have a word with us ... with them and ask if we can link together?" Because that's the way we seem to be getting inroads."*

*(Learning disability team leader)*

*"I did sit down one time and work out how many practices and how, how long it would take us, but it's very difficult to predict because we're doing this kind of cold call approach. If it was that the practice had to do it, we could estimate how long it would take us. But we really don't know, because it could take a long time to get a practice to the point where they're ready to do it. So it's very hit and miss really. I don't know, it'll take us years I think to work through all the practices."* *(Learning disability team leader)*

In absence of some sort of directive that health checks should be offered to people with learning disabilities, progress in rolling out the programme to all practice within the PCT was predicted to be slow and problematic. None of those involved questioned the value of these clinics and all recognised the resource issue as being the major barrier to roll out. Both practice and learning disability health professionals were thinking creatively about how to overcome this barrier.

## **4. Summary and Discussion**

It is well established in the literature that people with learning disabilities have an increased risk of ill health (e.g. Howells, 1986) and that they experience high levels of unmet health need (e.g. Wilson and Haire 1990; Harries 1991). This demonstrates the difficulty of identifying health need for both the person with learning disabilities and those who care for them. Barriers are also raised where health professionals provide services in circumstances ill suited to meeting the needs of these patients. Communication problems and gaps in knowledge on the health issues that affect this group, combined with lack of time in appointments, compromises the healthcare experience of these people (e.g. Lennox et al, 2000). These barriers to accessing health care imply that existing reactive healthcare systems are unlikely to adequately meet the health needs of this population.

In an effort to overcome barriers to access and improve the health status of the learning disabled population a number of initiatives have been trailed including attempts to improve communication (Dodd, 1999) and to provide additional information to general practitioners (Jones and Kerr, 1997). However the implementation of health check programmes has been the most widely trailed response to improving healthcare delivery to the group (Martin et al, 1997; Barr et al 1999; Cumella & Martin, 2002; Cassidy et al, 2002). These programmes have adopted a variety of formats including learning disability, and/or practice nurse, and/or GP led health checks. The health check that was the focus of this study was a joint nurse led programme between general practice and the joint learning disability team.

### **4.1 Access to healthcare**

This study, in line with earlier health check research noted above, recorded high levels of unmet health need. Initial health checks identified one or more health needs in 97% of attendees. However the study was concerned to establish whether the health check facilitated access to mainstream NHS service in addition to its health need identification role. Of those health needs identified, 84% were recorded as having some follow up healthcare contact. Quality of evidence on follow up access to healthcare was rated as part of the audit process and as a consequence it was confirmed in 76% of cases that the person had access to healthcare services in relation to identified need, and in another 14% of cases there was strong evidence that healthcare services were accessed. Those needs that could be dealt with within the health check appointment itself were most likely to be met, with 90% of preventative healthcare and 78% of health advice and education needs being addressed. However access to a range of other healthcare services was also confirmed in 88% of cases

requiring such input. It was difficult to establish whether services were accessed where this involved making a recommendation to patients that they contact other healthcare services themselves (with support) in response to identified needs, for example, to contact an optician for a sight test. In these cases the audit was only able to confirm service access in 29% of cases. This reflects the findings of Paxton and Taylor (1998) who found that not all recommendations to contact other services were followed through by carers.

For a number of health needs (41%) there was no recorded follow up. However an examination of audit notes suggested reasonable grounds for this apparent failure and it was considered that this may be due to there being no established system for recording when follow up was unnecessary, undesirable or not possible.

Second health checks covered a similar number of health issues as initial appointments (T1 mean 11.22 - T2 mean 10.17), and the number of health concerns noted changed very little (T1 mean 3.28 - T2 mean 2.77). At second health checks 78% of patients were recorded as having one or more health concerns. Half of the group had fewer health needs noted at their second check while 11% had the same number and 39% had a greater number of recorded health needs. 41% of needs identified at initial health checks were no longer recorded as a concern. This may have been due to improvement or successful management of health conditions, however it is also possible that the issue was overlooked in the latter check. It is unlikely, however, that a health issue that was continuing to cause concern would be overlooked in this way.

Persistent health concerns were evident, especially in relation to weight, blood pressure, diet and exercise. New health issues also emerged, however it was not possible to determine whether this was because the person's health had deteriorated between health checks, or the condition was checked but not identified or not checked at all at the first health check. This again reinforces the need to record lack of action as well as action in the course of health checks. This is particularly important in relation to this group where individuals suffer deficits in their capacity to recognise and communicate ill health and are therefore reliant on the assistance of carers and health professionals to be vigilant in this regard and also likely to experience support and care from a range of different individuals over extended periods of time. In these circumstances efficient record keeping is vital to ensure consistently high standards of healthcare provision.

As with initial health checks 84% of health needs noted in second health checks were recorded as having follow up. In 73% of these cases healthcare services were accessed in response to need and in a further 18% of cases there was good evidence that services were accessed. These figures are very similar to the rates established for initial health checks. There was no reported follow up to 23% of identified concerns, fewer than for initial health checks. Again arguably reasonable explanations were identified from audit notes as to why these particular concerns were not addressed. Such explanations included, that the condition minor compared to other health problems; it was a pre-existing managed health problem though still causing concern; the severity of the person's disability limited intervention options; appropriate action towards management of the problem had been initiated; the condition was identified through family or medical history but there were no current signs or symptoms to signify its presence.

As with the first health checks the need for preventative healthcare was most often identified and was usually addressed within the health check appointment. Health education and advice where required was also given at the clinic. Referrals to other healthcare services were made for 39% of patients, compared to 50% who were referred on after initial health checks. In 75% of cases these patients gained access to appropriate healthcare. Just over half of these referrals were to the joint learning disability team in relation to exercise programmes or weight, while the remainder were to the general practitioner, gastroenterologist and psychiatrist. This compares to first health checks where just less than 1 in 4 needs were referred to the general practitioner and 1 in 4 were directed to the joint learning disability team/learning disability nurse. Other referrals being to audiology, psychiatry, optometry, continence advisor or practice nurse. Referrals were therefore to a narrower range of services at second as opposed to initial health checks. The reason for this may be that once contact had been initiated at first health checks it would be unusual to need a second referral. Only one person was referred back to a service that they had accessed as a result of their initial health check and this was to a psychiatrist in relation to epilepsy.

Over the course of their health checks, 24% of the patients whose notes were audited in this study were diagnosed with a significant health problem. Four people's conditions were diagnosed as a result of a need identified at their first health check, two were diagnosed after needs were identified at their second health check and two more were similarly diagnosed after having a third health check. This suggests that ongoing health checks are needed if health problems are to be diagnosed and treated. The reasons for this may lie in the cumulative nature of addressing health need provided by this type of health check

programme. Patients with learning disabilities may not have every health issue checked at every health check. When a programme is new it may take time for the patient to feel comfortable with the setting and nurses involved. They may need preparatory work with the learning disability service before procedures such as blood pressure testing can be undertaken. Patients who are extremely anxious may only be comfortable with very general questions about their health status initially. As familiarity builds, however, further health issues may be broached. Alternatively, even where patients are already familiar and comfortable with the setting and nurses, there may be insufficient time to cover all areas of the health check. The audit demonstrated that risk factors such as weight, exercise and blood pressure tended to be checked at first and second health checks, whereas conditions which arguably affect fewer individuals such as asthma and allergies, were checked for very few people at either health check.

Martin (2003) reported a tailing off of referrals to other healthcare services after two years and a reduction in number of people referred and type of service referred to was noted here. However, the dual aspects of need for continuing contact to build confidence and trust, and to cover the wide range of health issues that may affect an individual, in addition to the finding that significant health problems were identified over three health checks and not only or mainly at the first health check, supports the argument for health checks to be implemented on a regular, as opposed to episodic basis.

Having examined the role of health checks in facilitating access to healthcare services the qualitative study explored the experiences of the general practices, joint learning disability team, and service users and carers involved in the service, to investigate the implications of implementing such a programme. Were health check services established for patients with learning disabilities on an ongoing basis, rather than as an event solely to establish a Health Action Plan, the experience of practitioners and service users involved in this initiative can be used to provide valuable guidance.

## **4.2 Implementing, running and using health checks**

Prior to implementing the health check programme practices tended to be aware of patients with learning disabilities who attended frequently. However practice nurse contact was rare compared to general practitioner contact. The practices viewed their services as equally available to patients with learning disabilities but recognised that this was often mediated by a carer and that they would often determine whether it was appropriate for the person to access general practice. Practices were concerned that their patients with learning disabilities

were not disadvantaged in relation to their other patients and saw involvement of the joint learning disability team as a way to facilitate provision of a 'well-person' check.

The learning disability service manager felt that where they had sought implementation but had met resistance, this was because general practices expected to identify a 'risk factor' for such surveillance. This is relatively straightforward for specific diseases or conditions, however the JLDT manager proposed that the 'risk factor' for this group was not a specific symptom but a consequence of learning disability. That is, the cognitive and communication problems faced by this population which impair their ability to recognise and report the signs and symptoms of ill health. Where these vulnerabilities are recognised as the 'risk factor' the logic of proactive surveillance becomes apparent.

Practices that had agreed to implement the programme reported few apprehensions about the programme beforehand. Managers tended to have concerns about the time demands the service would have on the practice, while practice nurses tended to have concerns about communication issues, providing appropriate care and misidentifying people as having a learning disability. Practice staff commented that although they were aware that some of their patients had a learning disability they had not conceptualised them as a group whose needs required special attention. The creation of a 'register' of patients with learning disabilities was the first step to enhancing this awareness.

#### Prevalence

Identification of patients with learning disabilities was undertaken in a variety of ways including use of the personal knowledge of practice staff alone; supplementing personal knowledge with computer searches; interrogation of computer systems using a range of search terms; and reliance on a list of patients supplied by the JLDT. These procedures were carried out prior to the implementation of the new GMS contract that requires computerisation of general practices for its operation. It is likely therefore that creation of registers in the future are much more likely to involve computer searching and comparably less emphasis on personal knowledge. However, the misidentifications that occurred were more likely as a result of computer searching than personal knowledge. Practices described some difficulties due to the large number of conditions or terms under which relevant patient notes might have been coded and the need for searches to be clear and comprehensive. Given the nature of learning *disability* and the confusion with milder learning *difficulties* that do not disable the sufferer to the same extent, establishing a comprehensive virtual 'register' is likely to be an ongoing process. However once established, practice staff were confident that registers



would be easy to maintain even where patient data relating to those joining and leaving the practice changed on a regular basis.

The numbers of people identified in practices varied between 10 and 40 depending on practice size. The numbers approximated to between 0.001% and 0.007% of list size, with the largest practices (>10,000 patients) reporting lower proportions of patients with learning disabilities (0.001% to 0.003%). However the smallest practice (list size 2,000 approx) reported the largest proportion of patients with learning disabilities (2%). The reason for this discrepancy is unclear. For small practices the presence of group homes for people with learning disabilities within their localities may be sufficient to raise the prevalence of these patients significantly in relation to total list size, however a similar presence would have comparatively little impact on prevalence amongst the list size of larger practices.

Based on their experience of running health check clinics practice nurses commented that clinics of no more than six patients were preferable, with a series of clinics repeated as necessary over shorter rather than longer timescales. Patients were offered half hour appointments for their checks and this longer appointment time was seen as crucial to delivering this service to them. There was much equivocation about the ideal timeframe for repeating the programme. Biennial clinics were perceived as more manageable logistically because they minimised demands on both practice and learning disability nurses and this was seen as acceptable for people who were generally well or attending disease specific clinics in tandem. However the underlying 'risk factors' of difficulties identifying need and seeking help meant that practice and learning disability nurses were concerned to leave repeat surveillance for this long. Carers also supported the provision of annual as opposed to biennial health checks.

### ***Resources***

After two or three cycles of health check clinics practices appeared to feel some ownership of the programme but still regarded the learning disability service as having a role in initiating ongoing clinics. Running clinics demanded resources from practices and learning disability service alike. For practices this involved a room and practice nurse time, which was estimated at between 12 and 15 hours over a number of months. This commitment was considered comparatively small and some managers felt the cost was easily absorbed by the practice. The resource commitment from the JLDT was significant because they were involved in clinics and meetings for the same numbers of hours as practice nurses but also because they distributed appointments and followed these up, where considered appropriate, with phone

calls to clarify for patients what the check was for. This commitment was then multiplied by the number of practices running health checks. However obligations under the Valuing People white paper in regard to facilitating access to healthcare and providing health action plans meant that the service regarded the resource expenditure as necessary. It was provided by prioritising health checks over other services.

Practice staff described the experience of running health check clinics as generally positive. The clinical skills required from the practice nurse were the same as for other well-person checks, however team working with the learning disability nurse gave them knowledge of the full range of services available to these patients and, for some, raised awareness of patients with learning disabilities within the practice. These nurses felt that they would be more likely to recognise a new patient with learning disabilities and to alert the JLDT. For their part learning disability nurses gained greater awareness of the working practices in general practice which enhanced their own practice within this setting and in approaching new practices.

### ***Service Users***

Carers reported that service users answered questions on their own behalf with some intervening occasionally if the person could not answer. Service users confirmed that they spoke to the nurses, however individuals commented that they were unsure what the checks were for, couldn't follow all the questions, or spoke on their own behalf only occasionally.

Health checks were perceived by nurses and carers as appropriate for people with all levels of learning disability. For people with mild learning disability, who may have limited or no contact with services on a regular basis, health checks were seen as a useful link both to ensure that health appointments were being kept and to provide access to other services (specialist and mainstream). For those with more severe learning disability, who have correspondingly greater health needs coupled with increased difficulties in recognising and communicating signs and symptoms of ill health, the health check was seen as a valuable opportunity to spend time investigating common health issues for people with learning disability in an ongoing way that built relationships and trust in their general practice.

Unsurprisingly, carers were seen as key to the operation of health check clinics through their enabling role. However the clinics were described as meeting their need for reassurance about the health of the person they cared for, by both carers themselves and nurses interviewed. Alternatively, some nurses also described some parents' suspicions about the

motives behind health checks. Monitoring for signs of abuse, or for signs that carers and/or the person they supported were having difficulties coping at home were raised as perhaps a secondary role for, or unintended consequence of health checks.

### ***Impact on services***

Conducting health checks meant that other activities within the practice had to be cancelled or postponed. However the practice staff described their patients with learning disability as equally entitled to their attention, hence no negative impact on other patients was described. The experience of conducting these clinics was felt by some nurses to have enhanced their interpersonal or communication skills to the benefit of other patient groups who require simplified, clear explanation.

Practices were positive about continuing the programme and most wished this to continue as a joint practice and learning disability service because each nurse was considered to bring different strengths to the clinic. However other models were proposed including moving to generic well-person appointments after an initial practice/learning disability health check. In the absence of a directive or incentive for practices to implement health check clinics, roll out to other practices within the PCT was predicted to be slow and problematic because the resource issue would be likely to be seen as a major barrier. Practice and learning disability staff were thinking creatively about how to overcome the resource barriers, as indicated by the model mentioned above. Learning disability professionals noted the introduction of a new role of Assistant Practitioner within general practice, and possibly in the long run the JLDT, as being one way forward. These practitioners would be adequately skilled to perform health checks and could be provided with the information they required to know who to approach in relation to concerns raised by the health check. However they were at too early a stage in their development to be incorporated in current roll out plans.

## 5. Conclusions

Plans have been outlined in policy documents such as the NHS Plan (2000), to improve healthcare delivery to provide efficient and effective healthcare services to the whole population of the UK, and emphasised in the learning disabilities strategy document Valuing People (2001) that this population should use mainstream NHS services (with appropriate support). Access to services is recognised as a key issue with considerable effort expended in ensuring that waiting times for appointments with health professionals and for treatment are kept to a minimum. As outlined above, however, the particular facilitation needs of the population of people with learning disabilities demand a proactive NHS service if they are to gain access to services in a timely and efficient manner.

As a means to facilitate access to healthcare health checks appear to be an appropriate vehicle. Health improvement is difficult to ascertain in the absence of rigorous longitudinal studies, however if one accepts the premise that timely access to appropriate healthcare is essential to health improvement then access to healthcare is a useful surrogate. The access to healthcare demonstrated in the audit suggests that this group of individuals are likely to experience health benefits in the long run. The marginally reduced but repeated identification of health need and diagnosis of significant health conditions over a succession of health checks supports the need for regular rather than episodic (life event prompted) checks.

The implementation of such checks impacts directly on general practice and learning disability services, in particular on nurse time resources. However directives in the Valuing People white paper that people with learning disabilities access mainstream services, the health facilitation role of the learning disability service, and the requirement for health action plans, requires investment of resources. Comments from practice and learning disability professionals suggested that incentives, such as are available through the Quality Outcomes Framework of the new GMS contract, could provide the resource to get health check programmes underway.

This particular health check model as a nurse, as opposed to GP, led programme has a different potential to the latter model. The literature, and the experience of the learning disability team management in this study suggests that GPs, while happy for their patients with learning disabilities to have a health check, are unwilling to become involved in such programmes themselves. In the present study, comparatively few of the individuals required referral to their general practitioner, the bulk of their need was for preventative healthcare,

and/or health education and advice. Given this reluctance, and that the latter healthcare forms a natural part of the nurses' work, it appears appropriate that such clinics be nurse led.

A recent study of practice nurse experience of working with patients with learning disability in Glasgow, Melville et al (2005) confirmed the view expressed here by practice nurses that patients with learning disabilities are fully entitled to use general practice. Those nurses reported infrequent contacts with the group. They experienced difficulties with communication, the amount of information carers provided at appointments and in interacting with their patients but were unlikely to offer longer appointments. They also experienced knowledge gaps in relation to the needs of this group. Melville et al, suggest that training for practice nurses is required to improve delivery of primary care services to these patients. The study here suggests that such training is a natural by-product for practice nurses who work jointly with their learning disability colleagues to provide health checks.

The consultative report 'Building on the Best' (DH, 2003) suggested that health checks require investigation before they could be offered to people with learning disabilities on an annual basis. This pilot study suggests that offering health checks to all people with learning disabilities on a regular basis would bring health benefits to this population. However, the definition of 'regular' would need to be determined by available resources but should occur no less than once every two years. The experience of running health check clinics in the practices studied here suggests that standardised but flexible computer templates could be created to guide health checks and allow for ease of recording both actions taken and not taken. The rigorous recording of health information for this group is particularly important in light of their disabilities and the turnover in both health and social care staff they are likely to encounter as long-term service users.

## 6. References

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