

# **From the Cradle to the Grave: A literature review of access to health care for people with learning disabilities across the lifespan**

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***Report for the National Co-ordinating Centre  
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## **Executive Summary**

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### **Aims and objectives of the review**

To examine evidence on access to health care for people with learning disabilities across all age groups and levels of disability. To identify theory, evidence and gaps in knowledge relating to:

- the help-seeking behaviour of people with learning disabilities and their carers in relation to health care
- barriers and problems experienced by people with learning disabilities in securing initial and access to the full range of health services
- specific, practical and effective interventions which improve initial entry and/or continuing access to the full range of mainstream health services by people with learning disabilities.

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### **'Access'**

The definition of 'access' adopted for the review drew on that developed in the scoping document *Access to Health Care* (Gulliford *et al.*, 2001). Our definition included both 'having access', where an appropriate service is physically available, and 'gaining access', where the service is successfully used. A model developed by Gulliford *et al.* to illustrate the interactions of factors affecting access to health care was modified (see Figure A) to take into account the additional needs of people with learning disabilities, particularly additional features of their help-seeking behaviour. The model provided the conceptual framework within which the literature review was set. This framework included:

- wider determinants of health
- identification of need
- organisation of health care services
- 'entry' health care (first contact)
- 'continuing' health care (ongoing contact).

The review is timely in the context of recent policy initiatives on providing equitable access to health care within a modernized NHS. Modernization of the NHS includes, among other objectives, improving access to first-contact and continuing health care and reducing inequities in the use of health services by disadvantaged groups (Department of Health, 1997; Department of Health, 2000). Policies for people with learning disabilities (Department of Health, 2001) emphasise their use of mainstream NHS services (with support if

necessary), and introduce targets for general practices to identify registered patients with learning disabilities and to offer them a Health Action Plan by summer 2005. A new liaison role of 'health facilitation' is also being introduced, to improve access to and use of mainstream NHS services by patients with learning disabilities.

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## Methods

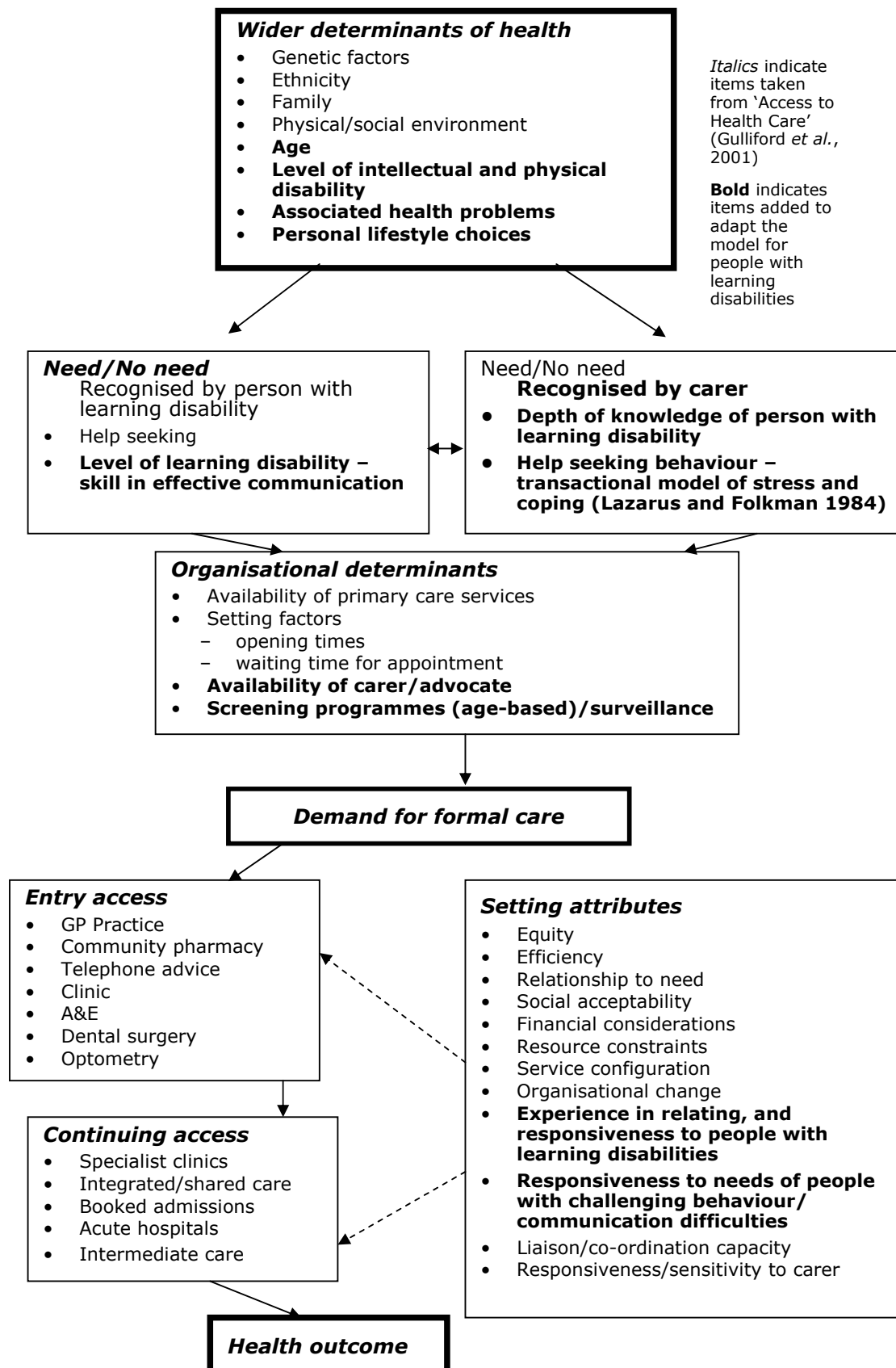
We drew on established methods for conducting literature reviews and adapted these to the diffuse and multidimensional topic of 'access'.

Broad inclusion/exclusion criteria for searching were initially set. English-language publications from 1980 onwards, using any study design, were sought relating to: people with learning disabilities of any age; one or more dimension of the access model; from countries that have a similar health service system to UK.

### ***Bibliographic database searches***

Bibliographic databases were searched, using both natural language and thesaurus approaches. This allowed for inconsistencies in indexing practices, while balancing the need for sensitivity and specificity

**Figure A Access to health care for people with learning disabilities**



## ***From the Cradle to the Grave***

The following electronic databases, libraries and web sites were searched: Medline; Embase; Cochrane Library; CINAHL; HMIC; Social Science Citation Index; ASSIA; IBSS; CareData; AgeInfo; Sociological Abstracts; PsychInfo; BEI; ERIC; SIGLE; ASLIB; ISI; Royal College of Nursing library; Royal National Institute for the Blind library; SCOPE; RADAR; Down's Syndrome Association.

We also identified references via the personal reference collection of the lead researcher; the *British Institute for Learning Disabilities Current Awareness Bulletin*; and regular scanning of relevant journals using the ZETOC table of contents alerting service. Other literature was identified via the citations of papers identified through electronic database and other searching. However, snowballing only began in the later stages of the project once critical appraisal and evaluation had begun, so full texts of these items were only obtained for literature that was easily accessible.

This process identified 2221 references (database searches = 1891; personal reference collection and current awareness bulletins = 92; snowballing and contacts = 238).

### ***Consultation***

The literature searching was supplemented by three consultation exercises:

- 1 consultations with representatives of national organisations of and for people with learning disabilities and experts in the field
- 2 discussion groups with people with learning disabilities and family and paid carers
- 3 a mail shot to researchers in the field and learning disability health professionals.

These consultations helped to refine terms for further literature searching, *inter alia* highlighting gaps where research is needed. They also helped in identifying grey literature.

### ***Evaluation***

Titles and abstracts were scanned by both lead researcher and librarian against the inclusion/exclusion criteria. Consequently, the full text was obtained of 839 publications identified as *potentially* relevant to the model. These were then read to decide whether the item met our inclusion criteria; 183 publications were judged relevant and went forward for further assessment. Of these, 24 were reviews of literature on access to health care with no original data and 77 were in areas of the model where a high volume of literature had already been identified and the preliminary quality assessment showed the papers were poor or insubstantial. None of these was included.

Eighty-two studies were fully evaluated including 15 qualitative, 62 quantitative and 5 mixed-method studies. The evaluation identified 5 highly rigorous papers, 22 rigorous and 46 less rigorous papers; 9 papers were rated poor. Many papers failed to attain higher evaluation ratings due to lack of methodological detail, which made judgements on confounding and transferability difficult. In the vast majority of papers, statistical analyses were descriptive, so quality evaluation of statistical techniques was largely inappropriate. Papers rated 'poor' were included only if they addressed an area or issue not covered in more highly rated studies, but their limitations were also stated.

The distribution of papers across the model was as follows:

- *Wider determinants of health*: health promotion (1)
- *Identification of need*: people with learning disabilities (4); parents/carers (23); others (1)
- *Organisation of health care*: GP services (9); dental services (5); optometry services (0); screening/surveillance (8); A&E (1); specialist outpatient clinics (10); acute services (2); therapy (5)
- *Entry access*: GP services (18); dental services (0); optometry services (1); community health services/A&E (4)
- *Continuing access*: specialist outpatient clinics (9); inpatient services (0); therapy (0)
- *Innovation*: communication aid (1); GP practice (1); GP practice-based health check (12); walk-in clinic (2).

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## Findings

We identified a considerable amount of literature on improving the health status of people with learning disabilities, of which 'access to health care' is a fundamental component. However, much of the literature that initially appeared highly relevant to the review was actually only marginally or implicitly related to access, but focused instead on practice issues or guidelines to care. Most evidence found was on identification of unmet health need and on GP services; evidence in other areas was scant. In terms of quality, literature tended to be less rigorous, with few highly rigorous studies.

Gaps in evidence were identified in some areas of the access model, and through issues raised in consultations.

## ***Wider determinants of health***

Access to health education or health promotion for people with learning disabilities can be a fruitful area for improving access to health care. People with learning disabilities tend to have poor bodily awareness so health education which clarifies the association between experiences of symptoms and health status could improve their ability to recognise health need or prompt action to access health care. However, we found almost no literature on this subject. The single study identified suggested that attempts to promote healthy lifestyle choices were not widespread; service providers with policies on health promotion, mostly specialist NHS trusts and hospitals for people with learning disabilities, were more likely to have implemented initiatives.

There was no information on access to mainstream health promotion or health education programmes by either people with learning disabilities or their carers. This area is under-researched.

## ***Identifying health need***

Identifying a need is an essential prerequisite to accessing health care. However, learning disabilities can impair the ability to recognise and interpret signals from the body and this creates the first barrier to accessing health care. We therefore examined the evidence on whether health need is identified in a timely manner, and appropriate access to health services sought, by:

- 1 people with learning disabilities,
- 2 family and paid carers
- 3 others in daily or regular contact with people with learning disabilities.

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

The limited evidence on identification of health need by people with learning disabilities showed they have difficulty identifying and/or communicating health need to carers and health professionals. Apprehensions about accessing services and perceived negative attitudes on the part of health care professionals may also act as deterrents to help seeking by more able people.

This is an under-researched area, where improvements in access to health services could be achieved by evidence of effective ways of helping people with learning disabilities to better understand their own health and health needs.

## **Family and paid carers**

As a result, many people with learning disabilities rely on family or paid carers to identify a need for health care. The evidence suggests that long-term relationships with carers facilitate identification of need, by enabling detection of changes from normal health status for people with more severe learning disabilities. However such relationships do not appear to facilitate identification of changes in health that occur gradually, such as sight or hearing loss. Moreover, carers may be reluctant to seek health care for problems that they consider 'trivial' or where they do not think the person would benefit from intervention, such as providing glasses to a person who does not read. There was evidence that carers also experience problems identifying mental health problems in the person they care for. Carers may be aware of symptoms, but fail to recognise them as indicating mental ill-health.

Research was scant on the fundamental communication issues that affect access to health care. This includes both communication by people with learning disabilities about their health, and by carers in establishing health need and communicating this to relevant health professionals. There is no research on the extent to which gender creates communication barriers – for example, men with learning disabilities may be profoundly inhibited in discussing sensitive issues with predominantly female care staff.

Although the decisions of parents and paid carers are crucial to seeking timely and appropriate health advice for people with learning disabilities, there is no research literature on this at all.

Carers working in residential settings may experience particular difficulties in helping their residents to access health care, for example because of staffing levels and turnover. However there is no research evidence on this. Similarly, literature was absent in relation to access to health care for people living in segregated settings such as village-style campuses, or forensic settings such as medium-secure units. Finally, although they may be an important route to health care for some people, the role of routine health checks carried out on residential and village campus residents in identifying health needs and facilitating access to entry health care was not explored.

## **Other professionals**

The consultations highlighted the roles of other professionals who are in regular contact with people with learning disabilities in facilitating access to health care. For example, consultation revealed that school nurses have a role in identifying health needs among children with learning disabilities, providing 'triage' on the need for more specialised medical advice and referral for health care. However, this was not reflected in the literature. Similarly the roles of teachers or day care staff in identifying health needs has not been addressed. Parents who

were consulted identified the Special Educational Needs Review as a forum through which health needs among children with learning disabilities can be raised, but again no research was found on this.

## ***Organisation of health care***

The organisation of health care is a further determinant of whether an individual 'has access' to health care. Organisational issues encompass both the availability and appropriateness of services, and the availability and effectiveness of a carer or advocate who can support the person with learning disabilities to get to and use health care. We therefore explored the evidence, and gaps in research, on whether people with learning disabilities 'have access' to the full range of health care services. We identified literature on the following organisational barriers:

- 1 shortages of provision
- 2 language barriers
- 3 physical barriers
- 4 lack of support in accessing services
- 5 inequity in access to screening and surveillance.

## ***Shortages of provision***

A shortage of provision was evident for some types of health services. However, these are likely to reflect general provision deficits rather than a lack of specific provision for people with learning disabilities. Several studies suggested a lack of, or inappropriate provision of mental health services to children, adults and older adults with learning disabilities. People with learning disabilities from South Asian communities were shown to have fewer contacts with psychiatrists than people from white communities, despite similar levels of need.

Less rigorous research highlighted inadequacies in the provision of sexual health services to people with learning disabilities, particularly for people who had suffered sexual abuse, and for men with learning disabilities who have sex with men and are therefore at risk of HIV infection.

There was evidence of shortages of physiotherapy and speech and language therapy services for people with learning disabilities. However, overall the amount of evidence on continuing health care services was small and may under-represent shortages of provision across the full range of services.

## **Language barriers**

Few studies directly addressed access to health care for people with learning disabilities from ethnic minorities. However, those that were found identified additional problems for children with learning disabilities from South Asian and Chinese families in accessing health care due to language barriers. Fluctuations in the availability of translators and, in some cases, their lack of competence in translating medical terminology, impeded access to health care.

## **Physical barriers**

Physical access difficulties for people with additional physical disabilities or the lack of communication aides for people with sensory impairments were identified in the literature as organisational barriers to access. Physical barriers specific to people with learning disabilities and those with low literacy levels included inaccessible notices and signs and unhelpful attitudes among health care staff, especially on larger sites.

## **Accessing services**

Research on the availability of support to help people with learning disabilities access health care was virtually non-existent. A single survey of local provision to support access to health services found problems with physical access to and communication barriers in using audiology services, optometry services, sexual health and family planning clinics, screening and immunisation clinics and chiropody services.

## **Accessing screening and surveillance**

We found no other studies that directly addressed specific issues relating to support for people with learning disabilities in accessing health care, despite the centrality of third party support to success in accessing services

Routine screening and surveillance is one organisational mechanism for creating access to certain health services. Evidence on the availability and appropriateness of population health screening programmes focused mainly on cervical and breast screening for women with learning disabilities. This research suggested that not all eligible women are invited for cervical screening or mammography and that inappropriate means may be used to inform those who are invited. Assumptions on the part of general practitioners and carers about the appropriateness of these types of cancer screening for more severely disabled women, have been reported in a highly rigorous study to result in failure to invite for screening and in non-attendance respectively.

Surveillance and screening programmes are important in providing opportunities for early detection of a range of health conditions, such as heart problems. However, there was no literature on the extent to which people with learning disabilities successfully access these services and subsequently receive appropriate advice or treatment. These are potentially important routes to accessing appropriate health care for people with learning disabilities and therefore require full investigation. Similarly, despite the barriers to cervical and mammography screening for women with learning disabilities noted above, there was no literature on proposed solutions to the difficulties outlined. This is the next logical step in ensuring effective provision of these services

### ***'Entry' access to health care services***

As the UK health care system revolves around a primary health care system where access to secondary services is largely through GP referral, most of the literature in this area covered access to and referral from GP services. A limited literature on other first-contact services was also identified. We explored evidence and gaps in research, on 'gaining access' to, and 'having access' to secondary health care through:

- 1 GP services
- 2 dental health care
- 3 optometry services
- 4 accident and emergency departments.

### **GP services**

A comprehensive, and largely rigorous, literature on the attitudes of GPs towards providing health care to people with learning disabilities reports general agreement among GPs that they are responsible for the day-to-day health care of these patients. However, many GPs also acknowledged that they lacked information on learning disabilities and the associated health problems that many people with learning difficulties also experience. Communication difficulties, time constraints and difficulties in carrying out physical examinations were all identified as affecting the GP's ability to provide an effective primary care service.

Overall, research shows that GP services are under-accessed by people with learning disabilities, taking into account their risk of having greater health needs. This under-use means that opportunities for preventive health screening and medication review in the course of consultations are also missed.

There is no research on the effectiveness of initiatives and interventions that were suggested might overcome some of these

barriers, such as offering double-length appointments to tackle barriers imposed by time constraints.

The relationship between level of disability and the type and appropriateness of health care accessed needs also to be addressed. A minority of individuals have additional needs that are so severe that use of 'ordinary' entry (first-contact) health service facilities is not feasible. Research is therefore also needed into provision of 'entry' health services by mainstream health professionals that are targeted at people with severe or profound learning disabilities, such as the provision of 'enhanced services' by appropriately trained GPs.

## **Dental health care**

Access to dental health services was addressed in a few studies. Children and adults with learning disabilities living with families appeared less likely to access dental services than either non-disabled children or adults living in formal residential care, respectively. The research suggests that mothers may be reluctant to take their son or daughter to the dentist to put them through what they perceived would be distressing experiences. Adults with learning disabilities living in informal family settings in the community were found to have higher levels of tooth decay than those living in more formal residential settings. They were reported as less likely to see a dentist regularly, or to have no dentist and only seek care when experiencing pain. Where people with learning disabilities used a number of services (day care and respite or residential care), some confusion and difficulty was reported about which carer was responsible for arranging dental appointments; this could result in losing registration with NHS dentists if the service is not used over a 15-month period.

This small literature on whether people with learning disabilities gain entry access to dental services focused on first-contact services. There was no literature on whether they subsequently have continuing access to specialist services such as orthodontics or prosthodontics.

## **Optometry**

The literature highlighted high levels of unmet need among people with learning disabilities in relation to impaired vision, but almost no literature was found on access to mainstream and specialist optometry services. A single thesis was found that described barriers relating to communication and examination in providing primary optometry, similar to those identified in relation to general practice. There is, therefore, an urgent need for more research on whether people with learning disabilities 'have' and 'gain' access to these services.

## **Accident and Emergency**

The literature on access to emergency services was virtually non-existent. There was some evidence that some parents of children with severe learning disabilities may be reluctant to access hospital services because they are perceived as upsetting for the child and potentially unproductive because symptoms were likely to be dismissed as being part of the child's disability (overshadowing).

Consultations suggested that the features of A&E services that facilitate access for children and adults with learning disabilities, particularly those with challenging behaviour, need exploration.

## ***'Continuing' access to health care services***

Many services to which people with learning disabilities may be referred involve ongoing contact over the longer term. In regard to conditions such as epilepsy, only periodic health appointments will be required to review experience of epileptic seizures in the recent past and review medication prescribed. In relation to other treatments, much more frequent contact is necessary to derive and maintain benefit. This is particularly the case with physiotherapy, where withdrawal of the service for even a few weeks may result in loss of flexibility or strength achieved in muscle tone. Continuing access to these services is therefore crucial to maintenance of optimal health status. However, the volume of evidence on access to, and ongoing use of, continuing health services was particularly small considering the wide range of services potentially involved, and also tended to be less rigorous, with only a few good-quality studies. As a result of these gaps, we were only able to identify evidence on the experiences of people with learning disabilities in 'gaining access' to:

- 1 specialist outpatient clinics
- 2 mental health care
- 3 therapies
- 4 audiology.

## **Specialist outpatient clinics**

Evidence was lacking generally on whether people with learning disabilities get to and successfully use specialist outpatient clinics, although a number of studies of users' perspectives suggested that negative or unhelpful attitudes towards people with learning disabilities among health care workers and professionals can affect their continuing use of these services.

Transition from child to adult services was a particular focus of research. The studies reviewed suggested that successful transition depended on an adequate supply of services relative to need and demand; availability of funding; and agreement over the respective responsibilities between child and adult services. It was suggested that often the attitudes and skills of staff, as well as assessments of ongoing need, were problematic. These difficulties were exacerbated for children with complex health needs who used several specialist clinics. Continuing access to epilepsy and mental health services throughout the child/adult service transition caused particular difficulties.

## **Mental health care**

The literature suggested that there are problems relating to the accessibility of mainstream mental health provision for children and adults with learning disabilities. In addition, there appeared to be confusion among carers over the respective roles of learning disability and mental health services. Research into the relationship and respective roles of mental health and learning disability services in the mental health care of people with learning disabilities is needed to clarify when and in what circumstances people with learning disabilities should use each service.

## **Therapies**

Access to physiotherapy and speech and language therapy is a particular need for this group. There is very little research on this topic and only one, poor-quality, study was identified. Moreover, consultations raised questions on the relative effectiveness of individual, as opposed to group, physiotherapy for children with learning disabilities, and ongoing access, that is, having obtained a service, gaining access to uninterrupted appropriate provision.

## **Audiology**

Research showed that people with learning disabilities have high levels of hearing impairments which had not been previously identified. However, no literature on access to audiology services by people with learning disabilities was identified.

## ***Innovations aimed at improving access to health care***

Most of the literature on innovations tended to be less rigorous in quality. Many of the problems experienced by people with learning disabilities in accessing mainstream health care have been recognised among specialist learning disability health providers and some local providers have sought to improve the situation. Unfortunately there has been little rigorous evaluation of the effectiveness of these interventions. It is possible that where an initiative has been implemented and works well, the need for formal evaluation may appear superfluous. However, evaluation is necessary for the dissemination of effective practice. Although a number of studies were identified, these may significantly under-represent the work going on among, in particular, community learning disability health services to promote access to health care. We identified the following evidence on innovations designed to improve access to health care for people with learning disabilities:

- 1 communication aids
- 2 support to GPs
- 3 health checks
- 4 walk-in clinics.

### **Communication aids**

Communication is a particularly important barrier to health care for people with learning disabilities and those who work with them, but only one pilot study, of a training package and communication aid, was identified. This study suggested that improvements in communication and understanding of health-related issues by people with learning disabilities could be achieved, but this one study does not constitute a substantial evidence base. There is therefore room for the further development and evaluation of communication aids and education programmes on using health services, for people with learning disabilities.

### **Support to GPs**

Although research confirmed that the majority of GPs confirm their responsibilities for providing health care to this group, some reported that they lacked information on learning disability; on the health complaints associated with specific syndromes; and on the specialist services available to these patients. There is therefore great potential for improving support to GPs that could help people with learning disabilities to 'gain access' to appropriate entry health care and to 'have access' to appropriate secondary health care. However, only one study was identified that evaluated such an initiative; this involved attaching a prompt card to selected GPs' records listing general

information relevant to the health care of people with learning disabilities and specialist services available. Evaluation of this intervention did not show improvements in preventive health care or changes in referral activities in comparison to a 'control' group. Further properly evaluated interventions are still needed to identify ways of offering effective and acceptable support to GPs providing health care to these challenging patients.

Despite being among the most challenging patients for health care staff to provide care to, people with learning disabilities represent a small percentage of the total population and therefore opportunities to work with them are correspondingly limited. We found no evidence of in-service education for health workers and professionals that aimed at improving access to services for people with learning disabilities and associated health conditions.

## **Health checks**

Difficulty in identifying health need is an important barrier for people with learning disabilities in accessing health services appropriately. This is caused both by a lack of capacity and knowledge on the part of the person with learning disability in recognising and communicating need and also by problems experienced by carers in identifying changes in health status and judging when to approach health services. Regular, proactive health checks can circumvent these barriers. High levels of unmet need were uncovered in all health check studies reviewed, but only two studies attempted to evaluate the success of health checks in subsequently facilitating access to appropriate mainstream health services. These studies found that carers influenced whether referrals recommended by health care professionals during a health check were followed through, and that referrals to mental health services failed to result in a specialist consultation, at least in the 12 months following the check.

Health check programmes have demonstrated their success in identifying health need but not in improving access to appropriate health care services. While the importance of their contribution to improving access through identifying health need should not be underestimated, it is now important to establish how changes in the organisation of health services can facilitate access to appropriate treatments.

## **Walk-in-clinics**

Two studies described walk-in clinics based in day care centres that aimed to facilitate access to mental, and general, health care respectively, but the effectiveness of these clinics could not be established from the reports. However, given recent policies promoting inclusion for people with learning disabilities within mainstream health services, these segregated services are unlikely to be widely supported.

There was no evidence on the role played by learning disability health professionals in supporting access to health care for people with learning disabilities, despite their potential importance in supporting mainstream colleagues to gain expertise in working with this group.

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## Overarching issues

### **Lifespan**

There are clear differences in the conditions and diseases that may affect people at different stages in their lives and in recognition of this the literature review adopted a lifespan approach. Only a limited literature was found in relation to access to health care for children, and literature relating to access by older adults with learning disabilities was almost non-existent. Research is needed into access to health services by younger and, particularly, older people with learning disabilities.

### **Ethnicity**

The evidence in relation to access to health care for people from ethnic minority communities was small and mostly part of studies on access to a wide range of services by these groups. Barriers to access to health services, other than language barriers, for people with learning disabilities from ethnic minority communities therefore need specific investigation.

### **Level of learning disability**

Severity of learning disability is likely to be related to level of health need and the presence of other difficulties such as mobility problems and challenging behaviour. We therefore tried to gather evidence on access issues in relation to people with different levels of learning disability. Unfortunately this was not possible. Most studies addressed themselves to 'people with learning disabilities' in general. Some studies drew samples that represented the range of levels of learning disability, but by doing so potentially masked issues specific to particular groups. The need for differentiation was reflected to some extent in our consultation groups, where more able adults with learning disabilities said they were able to use mainstream services, but parents reported having to use specialist services, such as the NHS community dental service, for children with severe learning disabilities. What is timely and appropriate provision to a person with a mild level of learning disability may not suit someone with a severe disability at all. This needs to be addressed in research.

## **Physical attributes of health premises**

The Disability Discrimination Act 1995 requires public service providers to remove, or provide alternative routes through, barriers which impede people with disabilities in using services. Provision of alternative means by which people can gain physical access to premises, and communicate with service personnel, is a minimum condition for accessing any service. We found little evidence to suggest that these organisational factors have been fully explored, or ameliorated.

## **Information**

The need for information was apparent across all parties involved in accessing or providing health services to people with learning disabilities. There was no research evidence on the provision of accessible information about services to people with learning disabilities or their carers. Through our contacts with learning disability health services, we are aware that some individual practitioners and primary care trusts are making appropriate information available. However, we found no evaluations of the effectiveness of any materials developed.

At the general practice level, as noted above, there appeared to be a lack of information about learning disability generally, and about the additional health problems that affect people with learning disabilities, particularly in relation to some syndromes. This type of information needs to be developed for the full range of health workers and professionals in both first-contact and continuing health services.

The multiple health needs of some people with learning disabilities often require contact with specialists at more than one hospital. Consultation with parents suggested that there were problems in hospitals sharing information for reasons of confidentiality. Repetition of investigations already carried out in another setting appears to be a risk associated with accessing continuing health care from multiple providers. This type of difficulty may be overcome by the introduction of the central electronic records, now proposed, which can be accessed by a range of health professionals working in a number of health settings.

## **Staffing**

A number of barriers to access identified in the literature relate to health care workers and these need greater exploration. Barriers appear to exist in professionals' attitudes, knowledge and interpersonal skills, and in the fragmentation of care between different health care professionals. However, there is no evidence on the reasons for these barriers, or how they might be overcome.

## **Health economics**

Improved access to services is likely to result in greater demand and thereby act as a drain on financial resources. It is unclear, however, whether given improved access the high levels of unmet need presently identified would be maintained in the long run, or whether they merely reflect a 'health backlog' due to difficulties in identifying need and seeking health advice in the past.

Improvements in identification of need and help seeking are likely to result in more timely health interventions, precluding the need for more expensive acute health services when health complaints have deteriorated. Health economics could model the likely effects of improved access in dealing with the 'health backlog'; and subsequent trade-off between increased financial demands due to improved primary and preventive health care, and savings made through reduced demand for more expensive secondary health services. Less material gains, in terms of improved quality of life for the person with learning disability, should also be taken into account, as well as the reduction of burden for carers that improved health would bring.

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## **Conclusion**

This evidence base provides a foundation for future research into access to health care for people with learning disabilities. Current NHS policies (Department of Health, 1997; 2000) emphasise the provision of equitable health services to the *whole* population of England. Similarly, policies for learning disability services (Department of Health, 2001) stress that people with learning disabilities should be able make full use of mainstream services (with appropriate support). General practices are expected to identify all people with learning disabilities who are registered with them by June 2004 and provide a Health Action Plan for all who wish to have one by summer 2005 (Department of Health, 2001).

The review suggests that family and paid carers, day care and education staff, as well as health care workers and professionals, can all provide 'health facilitation' for people with learning disabilities. However, specialist learning disability staff have a particular responsibility for facilitating the adaptation of mainstream services to the needs of their clients with learning disabilities, as well as facilitating access to health care for specific individuals.

Barriers to appropriate and timely access to health services operate both outside and within health services. However, the fact that some difficulties are encountered prior to first contact with health services does not mean that health service providers are unable to influence them. Strategies such as health education for people with learning disabilities and their carers may positively influence decision making

about access. Difficulties identifying and communicating health need on the part of people with learning disabilities may be overcome by adopting proactive strategies to identify need. Health checks, in some form, appear likely to perform this function and, if they are accompanied by referrals to appropriate health services, are ideally suited to providing the basis for Health Action Planning. What is unclear is the extent to which mainstream health services are currently equipped to deal with the increased number of approaches for health care from people with learning disabilities, and to respond appropriately to their specific needs, that improved access may prompt.

## ***Research recommendations***

- Research to improve identification of health need among people with learning disabilities:
  - to investigate health concepts among people with different levels of learning disability
  - to investigate help-seeking decision making by people with learning disabilities and their carers
  - to develop health education and communication aids to facilitate health need identification and communication by people with learning disabilities and their carers
  - to investigate the role of professionals in daily or regular contact with people with learning disabilities, such as school nurses, teachers and social carers, in identifying health need and facilitating access to health care.
- Research into changes in the organisation of health care:
  - to ensure the recommendations of the Disability Discrimination Act 1995 have been fully implemented with regard to physical changes and provision of communication aids for people with additional sensory impairments
  - to better meet the information needs of people with learning disabilities and their carers including information about services available, and signs and notices in health care settings
  - the effectiveness of measures to accommodate the special needs of people with learning disabilities and their carers when attending health premises, such as flexible appointment systems and separate waiting facilities for those for whom standard waiting areas are inappropriate
  - the success of health checks in providing evidence for health action planning and supporting access to mainstream health services.
- Research into health care delivery to ensure people with learning disabilities 'gain access' to services:
  - to develop effective and acceptable ways of providing information on learning disabilities, associated health conditions and specialist services to health professionals

### ***From the Cradle to the Grave***

- to develop appropriate undergraduate and in-service training on working with people with learning disabilities to improve expertise and confidence
  - to investigate the role of learning disability health professionals in supporting mainstream colleagues in providing accessible health care to people with learning disabilities.
- Research into ways to support people with severe and profound learning disabilities to access appropriate mainstream health care services and to develop complementary schemes where standard mainstream provision cannot be accessed.
- Research into access to health care for subgroups of people with learning disabilities including:
  - people with learning disabilities from ethnic minorities
  - people with learning disabilities living in segregated settings
  - older people with learning disabilities
  - children with learning disabilities.
- Research into access to dentists, opticians and audiologists.
- Research into access to A&E and continuing health care services.

# **The Report**

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## **Section 1 Introduction**

### **1.1 Aims and objectives of the review**

This literature review examines evidence on access to health care for people with learning disabilities across all age groups and levels of disability. It aims to identify:

- theory, evidence and gaps in knowledge relating to the help-seeking behaviour of people with learning disabilities and their carers in relation to health care
- evidence of the barriers and problems experienced by people with learning disabilities in securing initial and continuing access to the full range of medical, dental, therapeutic and health promotion services
- evidence of specific, practical and effective interventions which improve initial entry and/or continuing access to the range of health services by people with learning disabilities.

### **1.2 Background**

The term 'learning *disability*' refers to a significant intellectual impairment and deficits in social functioning or adaptive behaviour (basic everyday skills) that have been present from childhood (Foundation for People with Learning Disabilities, 2001). This is overlapped but distinct from 'learning *difficulties*' which indicates that a child has greater difficulty in learning than the majority of children of the same age, or a disability which prevents or hinders the child from making use of ordinary educational facilities (Warnock Committee, 1978).

UK prevalence of learning disability has been estimated at 230,000 to 350,000 people with severe learning disabilities, and 580,000 to 1,750,000 people with mild learning disabilities (Foundation for People with Learning Disabilities, 2001). The care needs of people with learning disabilities are wide ranging. More able people with learning disabilities are difficult to discriminate from people with general low intelligence and may need only limited supervision and assistance with budgeting for and paying bills, and general money management. People with the most severe learning disabilities are totally dependent on others in every respect.

People with learning disabilities are more prone to a wide range of additional physical and mental health problems than the general population. Their health care needs are therefore likely to be both

complex and long term. Furthermore, epidemiological studies predict increases in the numbers of people with learning disability both surviving the neonatal period and living into old age (Fryers, 1993; Carter & Jancer, 1983). New challenges therefore arise in relation to both the size and the ageing of the learning disabled population.

Moreover, people with learning disabilities also experience difficulties in recognising and communicating symptoms to carers and health professionals. People with learning disabilities, particularly those with limited communication, are likely to rely heavily on the familiarity of a close carer to recognise symptoms or indicators of ill health; to secure access to health care facilities; to interpret and communicate with health professionals; and to support compliance with treatment regimes.

Evidence is also emerging of a higher prevalence of people with learning disabilities among ethnic minority communities; in particular, children with learning disabilities from South Asian families are disproportionately represented among all children born with learning disabilities (Emerson & Hatton, 1999; Office for National Statistics, 1996). Additional language and cultural barriers may therefore further increase problems of access for this sizeable minority of people with learning disabilities.

The closure of long-stay hospitals for people with learning disabilities has generated new demands on mainstream NHS services to provide appropriate health care for people with learning disabilities. However, it is far from clear that mainstream NHS service providers have appropriate interpersonal skills and expertise to meet the specialised needs of this group. There is evidence that the health problems of people with learning disabilities are often unrecognised and therefore untreated (e.g. Howells, 1986; Wilson & Haire, 1990; Harries, 1991).

Current NHS policies (Department of Health, 1997; 2000) emphasise the provision of equitable health services to the *whole* population of England. Similarly, policies for learning disability services (Department of Health, 2001) stress that people with learning disabilities should be able to make full use of mainstream services (with appropriate support). General practices are expected to identify all people with learning disabilities who are registered with them by June 2004 and provide a Health Action Plan for all who wish to have one by summer 2005 (Department of Health, 2001).

### ***1.3 Definition of 'access'***

The scoping document *Access to Health Care* (Gulliford *et al.*, 2001) illustrates the diverse influences on entry and continuing access to health care. Gulliford *et al.* (2001) outline two ways in which the term 'access' is used:

- '*having access*' meaning a suitable service is available and it is physically accessible, and
- '*gaining access*' meaning successful entry into, and utilisation of a service appropriate to need.

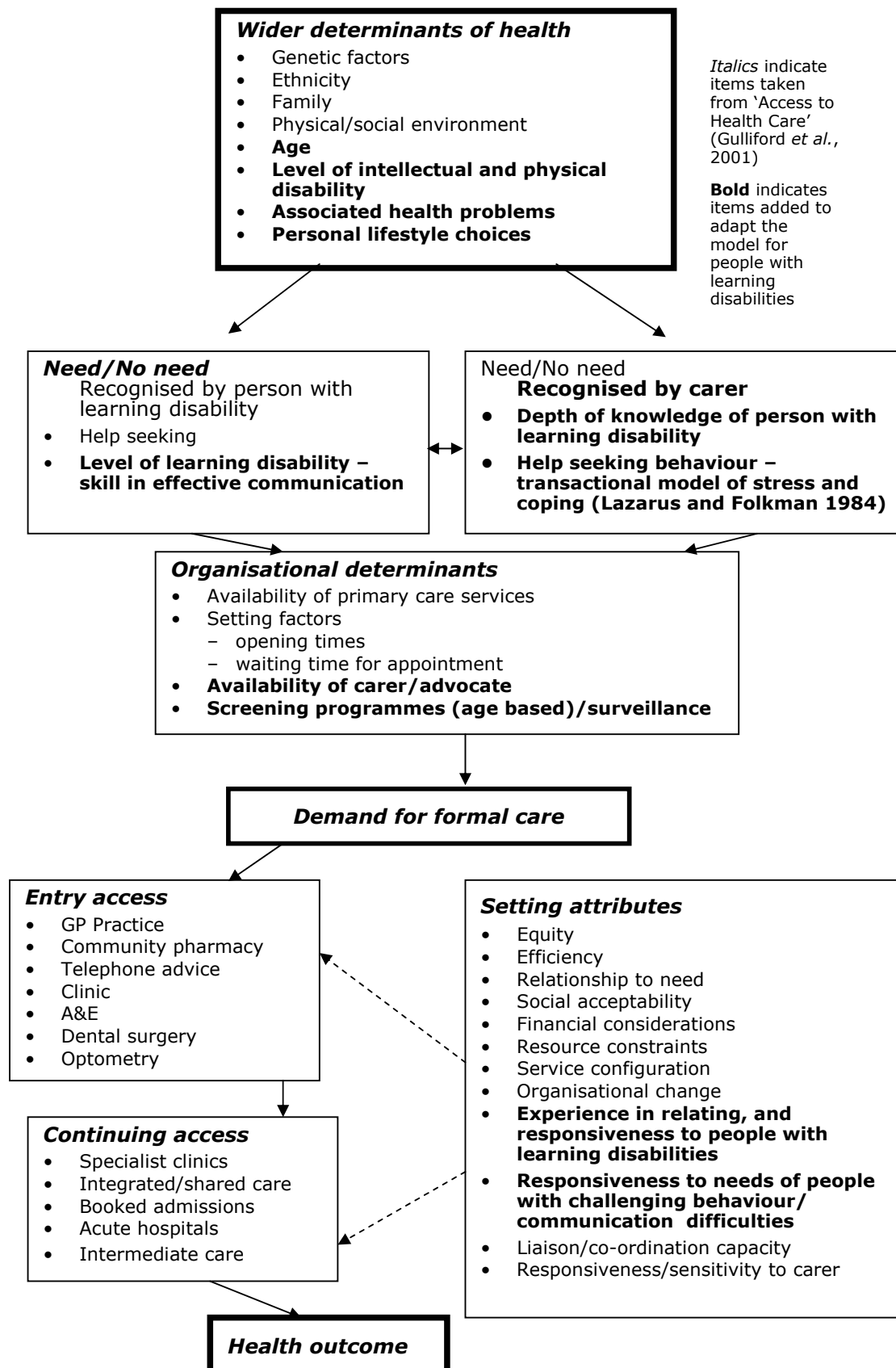
These two aspects form a continuum along which points of access may be defined.

Gulliford *et al.* developed a model to illustrate the interactions of factors affecting access to health care along the continuum (Gulliford *et al.*, 2001: 25). This model reflected the short-term, episodic nature of many of the health problems and service needs evident in non-disabled populations. However, ensuring equitable access to appropriate health care for people with learning disabilities depends on a number of additional factors, including:

- recognition and effective communication of symptoms and subjective well-being
- screening and monitoring systems appropriate to the higher incidence of some physical and mental conditions
- intermediaries (parents/support workers) who can support people with learning disabilities in obtaining health services and complying with treatment regimes
- the recognition by health care providers of their roles in ensuring access to additional services for people with learning disabilities who are already receiving ongoing health care
- specialist services which can treat associated physical, mental or behavioural problems
- the coordination of multiple health service interventions.

The Gulliford *et al.* model was therefore modified (Figure 1), to take into account the additional needs of people with learning disabilities, including the additional features of their help-seeking behaviour. The model provides the conceptual framework within which the literature review is set.

**Figure 1 Access to health care for people with learning disabilities**



## **1.4 The model of access to health care**

Figure 1 describes the whole 'access' continuum as may be experienced by people with learning disabilities. The stages of the continuum and their relationship to health care services are described below.

### **Wider determinants of health**

The wider determinants of health include many factors that are not amenable to change, such as genetic make-up or age; others, such as the physical or social environment, may be changed but they are not within the remit of health services to do so. Health services may influence personal lifestyle choices through health education or promotion by imparting knowledge and skills on lifestyle issues. People with learning disabilities are at higher risk of additional health problems but often experience communication difficulties.

The question, therefore, is: do people with learning disabilities 'have access' to health education or promotion? It appears unlikely that should they 'gain access' to conventional health education and promotion services, these will be appropriate to their needs. Problems of access to health services may therefore also affect access to health promotion and health education services.

### **Identification of need**

Establishing a 'need' for health care is the impetus for accessing health services. Prior to establishing need, 'having' access to health care services is incidental, and 'gaining' access irrelevant. Given that learning disabilities affect individual capacities to recognise and communicate health status, access will rely, to a greater or lesser extent, on the skills of a third party in recognising/interpreting the person's behaviour as indicating distress or illness. In these circumstances, parents'/carers' knowledge, both of the general condition and of the 'normal' health and behaviour of the person with learning disability, becomes increasingly important in ensuring access to health care. This stage of the continuum reflects the processes involved in help seeking.

Issues involved in help seeking are usefully illuminated by models of stress and coping which are likely to affect both the person with learning disability and their carer (Lazarus and Folkman, 1984; Lazarus, 1999). In order to seek help a person must first recognise that a stressor, in this case a health need, exists (primary appraisal identifying, in these circumstances, 'damage' or 'threat of damage'). Having established a need, seeking health care is only one option among a range of coping resources potentially available to the individual (secondary appraisal). Secondary appraisal involves evaluating the resources available to cope with the need, and establishing whether the need is worth spending the effort that will be

invested in coping with it (Antonovsky, 1987). Responses to need are likely to be influenced by socio-economic status, social resources and cultural differences (Nolan et al, 1996).

Effective communication presents a fundamental challenge in relation to identifying health need for people with learning disabilities. There are particular concerns about this aspect of access for people with learning disabilities who live in residential care homes, villages or communities (Flynn, 2000, personal communication), where a great deal depends on the continuity, expertise and responsiveness of staff. Individual perceptions involved in recognising need and deciding to act make this process doubly complex for people with learning disabilities, and a challenging issue for health care providers to overcome.

## **Organisational determinants**

The organisational determinants of health care are those that determine whether individuals 'have access' to services. They include issues such as the availability and accessibility of services. Unlike the general population, however, third parties constitute an additional factor in enabling access to services as they are likely to be involved in obtaining appointments; providing escort or transport services to a health care facility; and facilitating communication between people with learning disabilities and health professionals. They therefore have a considerable influence on whether and when a person with learning disability may physically 'have access' to health care services, as well as to an effective health consultation through their role in facilitating communication.

Health screening/surveillance is a continuing need for people with learning disabilities, particularly where their disability carries associated risks of certain illnesses – for example, heart problems, hypothyroidism and early onset dementia are known to be more prevalent in people with Down's syndrome (e.g. Howells, 1989). It is an important means to ensure appropriate access to both primary and secondary health care. However, the availability of appropriate screening is likely to reflect the norms of the non-disabled population. Infants and young children will be covered by universal screening and child health surveillance programmes, but local child health registers may not include information on more complex health needs or on health problems which occur after children reach school age (Glendinning *et al.*, 2001). Entry into adult life is met with a relative decline in routine health screening and monitoring, increasing the reliance on parents or carers being aware of likely health problems.

Financial disincentives are unlikely to affect the population of people with learning disabilities in the same way as the general population. For this group financial barriers to health care are more likely to exist within health care services than in the individual, because people with learning disabilities are usually exempt from prescription charges. However, financial considerations may well affect priorities within

services. It is well known that health service providers do not have the resources to give every person exactly the treatment they need at the moment they discover they need it. Decisions are made every day by doctors and others about who they will offer treatment to and when. As a result people with learning disabilities may not 'have access' to certain types of surgery or be able to register with certain health providers.

### **Entry access to health care**

Health services that provide the first point of contact with the public constitute 'entry access' to services. These are services to which individuals may refer themselves and require no professional assessment to determine access. These are the most frequently accessed services and they provide a 'gateway' through which people may 'gain access' to secondary or 'continuing' health services. Their role as both service providers and 'gatekeepers' means that they are a particular focus in relation to consideration of access issues. That is, not only do we have to consider whether individuals successfully enter and use primary care services ('gain access' to primary care) but also whether primary health care professionals appropriately refer them on to specialist secondary services ('have access' to secondary care).

### **Continuing access**

It is important that people with learning disabilities 'gain access' to specialist services in a timely and efficient manner. However, it may not be possible to 'gain access' to secondary health care where generic service provision is not responsive to their needs. Learning disability is also likely to impede understanding of diagnosis and treatment requirements. As highlighted in other stages of the model, third parties will be important in 'gaining access' to specialist secondary health services through their role as facilitators of access.

The long-term health problems experienced by many people with learning disabilities mean that health professionals themselves are more likely to be involved in detecting additional symptoms and problems, and making referrals to other services, than with non-disabled patients. Their continuity and expertise will have a significant impact, not only on outstanding levels of unmet need, but on access to other appropriate secondary or 'continuing' health services.

## **Overall**

The model allows for issues that equally affect people with learning disabilities and the general population, including unequal geographic distribution of services (the so-called postcode lottery), shortage of specialist health professionals (such as allergy specialists), and inadequacy of public transportation. However, this review will concentrate on the issues specific to this group.

There are vast differences in intellectual ability among people with learning disabilities as a whole and it is also known that health problems increase with increasing disability (see, for example, van Schrojenstein Lantman-de Valk, *et al.*, 1997). The capacity of the individual to respond to health need varies with level of intellectual ability. It is therefore important to consider the abilities and needs of individuals in any investigation. For this reason the review attempts to consider access issues specific to people with different levels of disability.

The review has adopted a life span approach. This was considered appropriate because there are clear differences in the conditions and diseases that may affect people at different stages in their lives. Children are susceptible to a range of diseases, many now controlled by vaccination, that are rare in adulthood. Adults have specific issues with menstruation, pregnancy and childbirth, or sexually transmitted diseases less common in adolescents or older adults. Older adults are likely to become increasingly prone to age-related deterioration in sight and hearing, and perhaps the onset of dementia. The capacities, life skills and needs of broad groupings of people with learning disabilities are therefore expected to vary over the life span.

## Section 2 Methodology

The aim of this project was to review the literature on access to health care for people with learning disabilities. The review was carried out between June 2002 and May 2003 by the lead researcher (Alison Alborz), with support from a Librarian (Rosalind McNally), a Research Technician (Angela Swallow) and a senior academic who supervised the project (Caroline Glendinning). There are established methods for conducting literature reviews of evidence on treatment (Khan *et al.*, 2001). However, methods for reviewing the literature on the ways in which health services are organised and delivered are still developing. We therefore drew on the established methods as a source of best practice while also considering other methods available for reviewing more qualitative data, and adapted these to the needs of the diffuse and multi-dimensional topic of 'access'. In defining 'access to health care' we drew on the model of Gulliford *et al.* (2001), which identifies the major dimensions as:

- **wider determinants of health** (pre-existing factors determining health)
- **identification of need** (personal recognition)
- **organisational determinants** (physical access dimensions)
- **entry access** (first-contact health services)
- **continuing access** (second- or further contact health services).

It was also part of our brief to review published studies of innovations designed to improve access to health care for people with learning disabilities as part of the literature review.

The main objectives of the review were:

- to develop the Gulliford model to incorporate particular dimensions of access to health care for people with learning disabilities
- to identify the literature on access as determined by relevance to the model and evaluate its quality
- to identify barriers and/or enablers of access to health care for people with learning disabilities across the life span including initiatives designed to improve access
- to identify gaps in the literature where future research could be targeted.

The methods used to deliver the objectives fall into seven main areas:

- 1 development of the model of access to health care
- 2 consultation exercise
- 3 development of inclusion/exclusion criteria for literature searching
- 4 identifying published literature
- 5 application and refinement of inclusion/exclusion criteria
- 6 development and application of quality criteria and data extraction tools
- 7 synthesis of literature and summary of review findings

This section of the report describes the methods used to carry out the literature review and is divided into two main parts.

- Section 2.1 covers the concepts which underpinned the review, initial criteria and the identification of literature. It describes the development of the model of access to health care, the consultation exercise, the development of inclusion and exclusion criteria, and how we identified the literature.
- Section 2.2 covers the data extraction and analysis which followed and includes the application of inclusion and exclusion criteria to the literature identified. It describes the development and application of quality criteria and data extraction tools, the method for synthesis of the literature included in the final review, and a summary of the literature identified.

## ***2.1 Underlying concepts, initial criteria and identification of literature***

### **2.1.1 Development of model of access to health care**

The Gulliford *et al.* (2001) model was first modified to take into account the chronic and complex health problems and care needs experienced by people with learning disabilities and the additional features of their help-seeking behaviour. Specifically, it was expanded to reflect the additional health problems often experienced by this group, but also to reflect life span and lifestyle aspects. Learning disabilities affect the ability to recognise and react to signs and symptoms of ill health and therefore third parties play a crucial role in access to health care for this group. The model was therefore expanded to reflect this role. Access to services is also affected by a number of additional setting attributes for people with learning disabilities, particularly knowledge of, expertise in, and responsiveness to this group. The expanded model provided the conceptual framework within which the literature review was set. A copy of the final model is included as Figure 1 in the Introduction (Section 1).

### **2.1.2 Consultation exercise**

The project assumed that a review of access to health care for people with learning disabilities should be informed by the views and experiences of stakeholders. The review included a short consultation exercise, the purpose of which was to:

- illuminate the model of access to health care for people with learning disabilities

- help refine and tailor our search strategies in determining what was 'relevant' literature by identifying barriers to accessing health care and any solutions adopted
- identify grey literature and ongoing research
- identify further contacts that may be able to provide information from their personal collections and knowledge relevant to the review

The consultation exercise was carried out between June and November 2002 and comprised three main elements:

- 1 consultations with representatives of national organisations of and for people with learning disabilities and experts in the field
- 2 discussion groups with people with learning disabilities and family and paid carers
- 3 mail shot to researchers in the field.

### ***Contacts***

Relevant organisations, including representatives of national bodies, local organisations and user and carer groups, were contacted by letter, telephone or e-mail. Individual researchers working in the field and learning disability nurses were also contacted. Contacts were sent information about the review and asked if they would like to contribute by commenting on what they felt the key issues to be or sending any publications they deemed relevant. In some instances the lead researcher conducted consultations face-to-face with the contact; others were conducted via e-mail or telephone. Notes were taken of each exploratory discussion, of issues arising in relation to access to health care. These were translated into search terms and used for final literature searching. Comments are also included, as appropriate, in the review (Section 3). Appendix 1 gives a list of all organisations and individuals contacted who contributed to the review.

***Discussion groups***

We held five discussion groups where we discussed the different aspects of 'access' as defined by our model. All discussion groups were convenience samples. These groups included:

- one group of paid carers working on a large campus and in community housing (n=8)
- two groups of three parents caring for children with severe learning disabilities
- one group of young people with learning disabilities who shared a supported/staffed house together in the community (n=5)
- one group of older people with learning disabilities living in various situations: independently, with 24-hour staff support, and with parents (n=6).

The lead researcher attended each discussion group together with another member of the research team. Discussion guides, designed to reflect dimensions of the access model (see Appendix 3), were used, and notes taken during the discussion groups were later written up. The lead researcher analysed group notes to identify access issues arising from discussion. The issues that had not previously been identified were translated in terms on which to conduct final literature searches. They were also used to describe areas where research was not found. Summaries of comments are included, as appropriate, in the review section of this report under the 'Gaps in research' headings. A list of additional issues raised in the discussion groups is included as Appendix 4.

***Research in progress and grey literature***

We searched the following databases and research registers to identify ongoing and completed research projects that may be relevant for inclusion. The following sources were searched using stage 1 of our main search strategy (see Appendix 5):

- NRR (National Research Register)
- CRIB (Current Research in Britain)
- REGARD (Register of Economic & Social Research Council)
- CORDIS (European Union Research and Development Database)
- REFER (Department of Health Electronic Register of Research Findings)
- RCGP Research Intelligence Database (Royal College of General Practitioners).

The lead researcher scanned all records retrieved and those projects judged potentially relevant to the model were sent a letter or e-mail by a research technician, providing information about the study and requesting copies of any outputs from the project that addressed access issues.

## ***From the Cradle to the Grave***

As a result of our identification of research in progress and contacts identified through consultation, 300 letters were sent out explaining the purpose and scope of the review and requesting information for inclusion. From these, 57 contacts sent information regarding their research or suggested other contacts. A copy of the letter sent to contacts is included as Appendix 2. The 57 contacts contributed 10 publications identified as suitable for further assessment for potential inclusion in the review.

The broad inclusion/exclusion criteria for the review were initially set as shown in Table 1.

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**Table 1 Initial inclusion/exclusion criteria**

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Population	People with learning disabilities of any age.
Relevance to one or more dimensions of access model	See Introduction (Section 1) and Figure 1 for details of model
Coverage	Limited to countries which have a similar health service system to UK (service funded from general taxation and notionally 'free' at point of access), e.g. Canada, Australia, for particular services and/or interventions; worldwide for studies addressing underlying concepts
Language	English language papers only
Study period	Papers were included from 1980 onwards; however, papers addressing health policy or institutional practices before 1990 were excluded due to recent changes in NHS and Social Service provision
Conference abstracts	Owing to limitations of time we did not include conference abstracts
Study design	Any – any study design was initially included although they may later be rejected if they failed to satisfy quality criteria

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Our decision not to impose any criteria for study design was based on the view that with a diffuse concept like 'access' to health care it would be unwise to limit the type of studies included, because the research evidence was likely to reflect a plurality of methods and approaches in keeping with the multi-faceted nature of the topic. As a key purpose of the review was to identify gaps in the research evidence and practical interventions to promote access, we also felt it was important not to base our initial inclusion criteria on a 'hierarchy of evidence' because this could exclude research judged to be of poor methodological quality which was still substantive in illuminating the model or 'innovative' in terms of potential for future development. In taking this approach we made a conscious decision to balance the 'signal' of a publication (our judgement of its potential value in illuminating access to health care for people with learning disabilities) against its 'noise' or poor methodological quality (Edwards, 1998).

As the concept of 'access' was diffuse, more exact criteria for inclusion and exclusion of literature emerged once the first stage of identifying

## ***From the Cradle to the Grave***

potentially relevant papers from initial literature searches had begun. This involved a partial deconstruction of the literature in order to identify underlying differences in approaches taken to the subject by authors and its relative value in illuminating the model of access to health care for people with learning disabilities. Listed below are some of the main narratives which emerged:

- descriptions of single services in professional journals with no evaluation or only anecdotal evidence
- reports of research carried out by campaigning organisations to publicise current lack of service responses or highlight good practice/innovation
- presentation of access-related issues (for example, referrals) from the perspective of professional 'management' issues – workload or demarcation of roles/responsibilities of different services, sectors and professions; part of professional discourse and not conceptualised as an access issue
- one-dimensional attempts to quantify 'attitudes' of different professional groups of staff towards people with learning disabilities
- attempts to identify unmet health needs among people with learning disabilities, by either planned or opportunistic screening followed by discussion of service responses (such as levels of use, communication and roles/responsibilities)
- discussion/debate on what models of service delivery and service planning should be used and strategic planning on which to base services for people with learning disabilities
- qualitative research aiming to understand meaning with holistic explanation of current responses of services to people with learning disabilities and to understand the context of health care for people with learning disabilities.

This process enabled us to identify more specific criteria for inclusion to apply to the findings of the literature search. These are summarised in Table 2 and listed in more detail in Appendix 6.

**Table 2 Expanded inclusion/exclusion criteria**

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Access to health education, health promotion, sexual health education, screening and information	Effectiveness and nature of health education, health promotion, sexual health education, screening and information
Communication of health need	Descriptions of interventions to improve communication, including training
Self-advocacy/help-seeking in personal health care	Participation on service user panels
Identifying health problems, stress and coping, practical support in accessing health care for parents/carers	Carer as therapist
Facilitation of access to health care for effects of sexual abuse	Problems of identification and support in reporting sexual abuse
Role of GPs/front-line staff in referral	Effectiveness of treatments/drugs
Challenging behaviour where it is an aspect of a health condition	Challenging behaviour where communicating social need
Organisational issues (geography, transport, appointments)	
Staff attitudes and knowledge, communication/relationships, practices/routines	Nature/effectiveness of treatment regimes
Issue of consent as barrier	Content of training programmes
	'How to' assess capacity to consent
Outcomes of specific initiatives and organisational development to improve access	'How to' descriptions of methods

## **2.1.4 Identifying published literature**

### ***Bibliographic database searches***

The main method used to identify literature relevant to the model was through searching bibliographic databases.

Our search strategy was based on the principle that a good quality literature search should:

- use both natural language and thesaurus approaches to searching to allow for inconsistencies in the indexing practices of bibliographic databases
- balance the need for sensitivity (avoiding non-retrieval of relevant items) and specificity (precision to retrieve only what is relevant).

With a diffuse topic such as access to health care it is more difficult to devise a search strategy which is highly specific. Accessibility is one aspect of the quality of health services and as such the literature of the topic reflects the communication of a wide range of dynamic organisational, professional and stakeholder issues.

***Devising a search strategy***

The development of our search strategy pursued the following iterative process. A full list of all the databases searched and search strategies employed is included as Appendix 5.

***Thesaurus searching***

The thesauri of major medical/health databases were studied to identify appropriate subject terms under which to search. Thesaurus searches were carried out linking preferred terms for access to health care with those for learning disabilities. The use of thesaurus searching was of limited value because the scope of the terms used varied across databases and was narrow in comparison to the dimensions of our model of access. However, the records retrieved from these searches helped to identify possible terms for natural language searching and identified further inclusion/exclusion criteria.

The terms used to describe people with learning disabilities in the major medical databases are inconsistent. There is overlap in the scope and definition of terms such as 'mental retardation', 'learning disabilities' and 'learning disorders'. The term 'mental retardation' is still used for indexing despite not being widely considered as an acceptable label for people with learning disabilities. Some databases use an educational definition, sometimes based on IQ, in others based on American legislation. This meant thesaurus searching was not particularly productive because we had to exclude many papers, for example, those covering children with a purely educational diagnosis of 'specific learning difficulties' such as dyslexia.

***Natural language searching***

To identify relevant terms to search for, the lead researcher and the librarian studied the records retrieved from the thesaurus searches and brainstormed to identify additional terms relevant to access to health care for people with learning disabilities. From this exercise we generated:

- a list of terms either currently or previously applied to people with learning disabilities; the changes in attitudes, policies and assumptions, leading to changes over time in language and terms applied to people with learning disabilities, led us to use a range of terms to identify potentially relevant literature
- a list of terms reflecting concepts and issues closely related to access
- a list of related terms covering specific conditions or health issues of particular relevance to people with learning disabilities.

These three sets of terms were combined and formed the basis of our initial search strategy.

***Further searches conducted as a result of the consultation exercise***

As a result of the consultation exercise we identified a number of additional areas of concern in access to health care for people with learning disabilities which had not been covered by the initial searches. We therefore returned to the literature and carried out some additional natural-language searches in these areas.

We searched retrospectively from 1980 to July 2002 on the basis that, though the terminology and health policy applied to people with learning disabilities has changed, health care needs will be relatively constant.

***Search limitations***

We limited our search to publications in English, from 1980 onwards and excluding conference abstracts. Owing to the large number of non-relevant records initially retrieved, we limited our final search strategy to terms occurring in the title of the record on the assumption that this was likely to confer greater relevance.

From our initial search, theoretical papers published anywhere in the world were retained. However, papers reporting original research findings from the USA were not retained. This was to reduce the number of references and because the systems of delivering health and social services in the USA meant many of the papers were less relevant. Our main focus was on countries with similar systems of access to health care and delivery to that of the UK, such as Australia and Canada. In our further searches, following the consultation exercise, we included US papers because we were targeting areas where we had identified little or no literature from our initial searches.

Electronic databases vary in their accessibility and sophistication of search and retrieval mechanisms. It was not possible to execute the full search strategy on all databases, because the facility for wild card searching or to combine substantial numbers of free-text terms was either not available or not effective. In these cases all records with the key terms to describe people with learning disability in the title were retrieved and then scanned for relevance to our model. A judgement was made by the librarian carrying out the searches as to whether the record was likely to be relevant to our model of access, and records judged as such were saved.

***Current awareness bulletins, scanning and personal reference collections***

We also identified potentially relevant references via the personal reference collection of the lead researcher. In order to monitor the publication of literature throughout the duration of the project the following methods were used:

## ***From the Cradle to the Grave***

- We subscribed to the *British Institute for Learning Disabilities Current Awareness Bulletin*, which includes a health section.
- The lead researcher also regularly scanned the contents of all the main learning disability journals for the duration of the project by setting up a profile using the ZETOC table of contents alerting service (including *Mental Retardation*, *American Journal of Mental Retardation*, *Journal of Intellectual Disability Research*, *Research in Developmental Disabilities*, *Journal of Learning Disabilities* – New York, *Journal of Learning Disabilities* – London, *Journal of Applied Research in Intellectual Disabilities*).

### ***Snowballing***

Relevant records were also identified by checking the citations of papers identified through electronic database and other searching. This method produced additional references which had not been identified by the other methods. However, given the nature of the topic and the limited information available from a citation and contextual information from the part of the publication in which it was referenced, it was often difficult to establish whether the reference would be relevant. Snowballing only began in the later stages of the project, once critical appraisal and evaluation had begun, and therefore we only had time available to obtain the full text of literature which was easily accessible. Consequently additional potentially relevant references identified via this method were only obtained in full text if they were accessible immediately via the electronic journals collection from the John Rylands University of Manchester Library. This constituted in the main journal articles from 1998 onwards. The number of potentially relevant references identified as duplicates increased steadily while using this method, increasing our confidence that a point was being reached beyond which only marginal gains, in terms of new references, would be made and saturation point was being reached.

All search results were saved in a database using Reference Manager bibliographic software.

### **2.1.5 Search results**

Table 3 shows the number of potentially relevant references identified.

<b>Table 3 Number of references identified by search method</b>	
<b>Methods</b>	<b>Number of references identified</b>
Database searches	1891
Personal reference collection and current awareness bulletins	92
Snowballing and contacts	238
<b>Total</b>	<b>2221</b>

## ***2.2 Identification of literature for inclusion, data extraction and synthesis***

### **2.2.1 Application of inclusion/exclusion criteria**

All the bibliographic records of potentially relevant literature were assessed by the lead researcher and the librarian individually, and designated as either 'obtain paper' or 'not relevant'. All the records were then checked for agreement between researchers and those on which there was disagreement were re-assessed. In pursuit of a systematic and thorough approach we obtained the full text of articles if we were unable to judge the relevance of the paper from the title and/or abstract alone.

The decision as to whether a record was potentially relevant, and the full text was to be obtained, was based on our judgement of its potential relevance to the model of access. Reviewing the literature systematically in an area of service organisation and delivery was not, therefore, a linear process. Where it is not possible to carry out a highly specific search strategy it is necessary to carry out further 'funnelling' (Hawker *et al.*, 2002) of the initial search results before final inclusion and exclusion criteria and a definition of what is relevant can be determined. It became clear that in a literature review of this type, criteria for inclusion/exclusion and what constitutes 'relevant' studies cannot be fully determined in advance; these emerge via a process of translation. It is not therefore possible to define *a priori* a search strategy with a high level of specificity.

The first stage of 'funnelling' and marking up of records was based on the limited information available in the titles and abstracts of bibliographic records. Where an abstract was not available, relevance had to be judged on the title alone. Abstracts, where available, should assist the user in determining relevance but are of variable quality (Hartley, 1995). This affects their utility. The provision of abstracts

was generally much better from the medical/health databases and poorer for social science.

The literature identified fell into a number of categories. Bibliographically it reflected different types of publication, such as books, grey literature and journal articles. Methodologically it included qualitative, quantitative and theoretical work. However, the literature could also be categorised in terms of the wide range of themes, disciplines and paradigms it reflected. This is in keeping with literature synthesis as a form of ethnography. The role of the synthesiser is then to identify what the key metaphors and concepts are in order to understand competing 'world views' of a topic (Noblit and Hare, 1988).

All the publications identified represented forms of narrative, and therefore issues of audience, language and knowledge emerged. One of the further outcomes of the review process was therefore to identify these competing 'world views' and evaluate their relative contribution to illuminating our model of access to health care for people with learning disabilities. In carrying out this process we were aware that the review was proceeding to a synthesis of the findings which would reflect our perspectives as well as the substance of the literature and that this was a feature of literature review in more diffuse, 'soft' topics.

As a result of this initial assessment we identified 839 records as potentially relevant on the basis of the information available. The full text of these items was obtained and they went forward to the quality assessment stage.

## **2.2.2 Application of quality criteria and data extraction**

### ***Evaluation of 'quality'***

The quality evaluation criteria used in this review have drawn on the work of the Health Care Practice Research and Development Unit, University of Salford (2001a; 2001b). Our approach to the synthesis of qualitative and disparate data also drew on the work of Noblit and Hare (1988), Hawker *et al.* (2002), Popay *et al.* (1998) and Mays and Pope (2000).

There is considerable agreement among researchers about the most important indicators of methodological and epistemological quality, many of which may be applied to both quantitative and qualitative research. As the literature around access to health care is diverse in its methodology, criteria to evaluate quality were adopted depending on whether the study had a quantitative, qualitative or mixed-method focus. A quality evaluation tool was developed which was specifically designed to incorporate the multifarious nature of research evidence on diffuse topics such as 'access'. Given the inadequacy of many of

the paper titles and/or abstracts available from electronic database searching, and the extensive grey literature in the area, it was necessary to devise a parsimonious tool which, while evaluating quality, would also provide opportunities for the reviewer to decide whether further analysis would be unproductive. To this end two opportunities for data rejection were included before final full appraisal and evaluation of research quality. A copy of the full assessment tool is included as Appendix 7.

The tool was piloted on a sample of six papers prior to the quality evaluation phase. The lead researcher and the librarian assessed three papers separately and the results were compared to identify issues requiring clarification and assess consistency of approach. A further three independent assessments were completed to ensure inter-rater reliability. The assessment tool was then converted into a database format using the Microsoft Access software and the evaluation of all remaining papers carried out by entering data directly onto the Access database.

As a result of the pilot exercise, some amendments were made to the database version of the tool to extend the options for classifying the literature by study type, study design, age group and disability range. This included the addition of an 'all' category to cover literature which applied to all age groups and across the range of disabilities. We also extended the number of coding boxes for identifying the areas of the model which a publication explored, from three to five.

*Quantitative studies* were assessed with respect to the object of the research: conceptual/theoretical vs. service evaluation; the data sources; research instruments used; and data collection procedure. The assessment drew on the work on quality evaluation carried out by the Health Care Practice Research & Development Unit, Salford University (2001). The primary assessment was on the basis of whether confounding might offer an alternative explanation to the findings and whether the study built on an existing body of research or generated new knowledge. Studies were rated as follows (Reeves *et al.*, 2000).

- 1 Little confounding or confounding controlled or large sample used. Data collected contemporaneously. Knowledge indicator met.
- 2 Main confounders partially controlled or shown to be low-level. Wide evidence base and knowledge indicator met.
- 3 Confounders not controlled or measured, or measured and found moderate. Involves specific service or opinion only but knowledge indicator met.
- 4 Main confounders operating or likely to be involved. A single service and very small sample or knowledge indicator not met.

*Qualitative research* was assessed using established standards (Popay *et al.*, 1998). Consideration was given to whether themes emerging connected with existing bodies of theoretical knowledge or generated

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new understanding, as well as the validity and adequacy of the studies.

Validity and adequacy were judged through:

- *data quality* – relevance, clarity of description of data collection processes
- *theoretical adequacy* – clarity of description, logic of analysis, imagination in interpretation; coherence, fairness, honesty, generalisability and transferability of findings
- *policy relevance* – extent to which research addresses issues of concern to practitioners and policymakers; extent to which it empowers service users.

In applying these markers the primary focus was application of the knowledge indicator with most weight given to studies meeting the requirements for interpretive validity. Studies were then rated as follows:

- 1 All or most quality indicators met.
- 2 Main quality indicators met including knowledge indicators.
- 3 Some lack of detail but meets knowledge indicators.
- 4 Some lack of detail including knowledge indicators.

### ***Stage One***

The full text was obtained of all 839 publications. These were then assessed individually either by the lead researcher or the librarian to decide on the basis of the full text whether the item met our inclusion criteria of relevance to the model. Any publications where the assessor was unsure or doubtful were discussed jointly to agree a status.

After allowing for accurate recording of the paper identifiers (authors, title, source, year, unique search ID number) and study type (original research report, review etc.), the first part of the form requested confirmation that the paper addressed one of the issues of interest generated by the model adopted for the research. Papers found wanting once the full text was available were abandoned at this stage and the reason recorded.

Of the 839 potentially relevant items of which the full text was obtained, 656 were subsequently judged to be not relevant to the model on considering the full text. The remaining 183 were judged relevant and went forward for further assessment.

### ***Stage Two***

Twenty-four of the papers proceeding to Stage Two were reviews of literature on access to health care with no original data. These papers were read with a view to ensuring relevant original research had been identified and retrieved. Every paper representing original research and was read fully and assessed against a universal set of primary quality indicators. This included establishing the issues under investigation, the aims of the study in relation to these, and the methodological and analytical techniques employed. These aspects of the study were then evaluated for clarity and rigour. The main areas of the model to which the study applied, age groups and disability range were also identified. At this point papers in areas of the model which had achieved a high volume of literature, or where the preliminary indicators showed the paper lacked quality, were not assessed further (n=77). Papers which scored highly on the primary quality indicators and/or those which applied to areas of the model for which only a low volume of publications were identified proceeded to a more detailed quality assessment based on their study design. If papers that lacked quality remained the only source of evidence on an issue their findings were included in the review but their limitations made explicit.

### ***Stage Three***

Preceding the final stage of quality appraisal the papers were evaluated according to more specific quality criteria for qualitative, quantitative or mixed-method studies. The quality evaluation score (1–4) was then awarded which signified the rigour with which the study had been conducted. The quality evaluation assessment and process of data extraction included a translation of the literature using both literal and idiomatic techniques. The main details of each paper were transcribed word-for-word (literally) from the original text onto the quality evaluation pro-forma in an effort to accurately represent original findings. However, using a more heuristic approach to reviewing the literature we also added our own comments on the quality, paradigms and approaches used in the research and how these compared and contrasted with previously reviewed literature. This idiomatic approach is based on translating the 'meaning' of the text as well as its literal meaning and has been identified as a precursor for synthesising and interpreting qualitative literature (Noblit and Hare, 1988) into a new construction or dialectic. As the final stage of quality appraisal progressed, our understanding of the literature and its relationship to the model deepened as a result of this process.

Eighty-two studies were identified as relevant to the model of access to health care. Details of studies may be found in Appendix 8. The papers include 15 qualitative, 62 quantitative and 5 mixed-method studies. The evaluation phase allocated 5 papers the top rating of 1; 22 papers were rated 2; 46 papers rated 3; and 9 papers rated 4.

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Many papers evaluated failed to attain higher ratings due to lack of detail in the methodology, which made judgements on confounding and ability to generalise difficult. The nature of the subject under investigation meant that statistical analysis in the vast majority of papers was descriptive with no recourse to sophisticated data manipulation techniques. Therefore, these considerations in evaluation were diminished. Consequently, we considered many of the papers given a rating of 3 were adequate in terms of the soundness of the data on which conclusions were based. We therefore considered it appropriate to include papers rated 1, 2 or 3 in the review as appropriate. However, if a paper given a rating of 4 addressed an area or issue not covered in more highly rated studies they were included, but their limitations also stated.

## Section 3 The review

The review will follow the model of access to health care that has guided the literature searching throughout. A brief discussion of the wider determinants of health, and the health education and promotion activities that affect lifestyle choices, will be followed by exploration of the issues pertinent to accessing health care as they relate to:

- identification of health need
- the organisational determinants affecting access to health care
- access to 'entry' health services – those to which the general public may refer themselves and which form gateways to access specialist health care
- access to 'continuing' health services – those to which one has to be referred by another health professional.

The final section of the review investigates innovations reported to improve access to health care.

At the start of each section a table summarises the papers referred to in the text and the quality of the evidence is then briefly discussed followed by presentation of the findings. The summary table provides the full reference of the paper, the type of methodology used, the age group and disability level of participants, and the rating given in the evaluation stage. Ratings of 1 (highly rigorous), 2 (rigorous), 3 (less rigorous), and 4 (poor) are represented in the text by ID numbers in **bold**, plain, *italic* and italic underlined font styles respectively. At the end of each section gaps in the literature raised by the consultation exercise are addressed. It is important to note that the consultations constitute comment only and not data.

Not all papers stated the age or disability level of the people with learning disabilities who were investigated. This was particularly the case in relation to studies collecting information from carers. The majority of these studies have been included in the text relating to 'Adults' unless there were definite signals in the papers that the group in question were in fact children or adolescents, or older adults.

It was a particular difficulty with the literature that 'people with learning disabilities' were often treated as a homogeneous group. This review attempts to take account of disability level considerations; however, given the tendency of the literature to treat 'people with learning disabilities' *en masse*, this has presented real problems.

### **3.1 The wider determinants of health**

Many of the wider determinants of health are not amenable to change, as noted above. However health services may have an impact is on lifestyle choices, largely through appropriate health education and promotion. This section searched for evidence on access to health education or promotion for people with learning disabilities.

#### **3.1.1 Health education and promotion**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8216	Turner, S. 1996. 'Healthy bodies, health minds', <i>Community Care</i> 5-10 January: 24-25	Quantitative	NR*	NR	3

\* NR = not recorded in paper

Only one study was identified that looked specifically at this area of health provision. This study was rated as less rigorous in quality, due to lack of detail on methodology. The evidence base on access to health education or promotion is therefore almost non-existent.

#### **Children**

There may be an assumption that the health education and promotion needs of children with learning disabilities are met by their schools; however, we identified no papers which investigated the role of school nurses or teachers in this area. This would be a logical place to start the education of people with learning disabilities in the types of life choices that may enhance their ability to go on to live active and fulfilling lives as adults.

#### **Adults/older adults**

Although the study<sup>8216</sup> on promoting healthy lifestyles identified does not specify an age group, the service providers participating suggest that it related to an adult population. Service responses to national policy on healthy living (Department of Health, 1995), where they occurred, appeared to have developed piecemeal rather than emanating from local policy on health promotion for service users. Trusts or hospitals for people with learning disabilities were more likely to have written policies. Overall services with policies tended to be more active in promoting healthy lifestyles than those who did not.

Access to health education for adults is potentially a fruitful area for improving access to health care. People with learning disabilities are known to have poor bodily awareness (see, for example, March, 1991) so health education, which could clarify the association between daily

activities and subsequent poor health, is perhaps one way of improving ability to recognise health need and prompt action in accessing health care.

***Issues raised in consultations***

Gaps in research were identified in relation to:

- provision of appropriate school, college, or residential campus-based health education for children and adults with learning disabilities
- provision of health education for parents and carers
- provision of health education for children and adults with learning disabilities and family carers from ethnic minorities.

Carers in residential facilities suggested that health education for people with learning disabilities and carers could be a productive way of improving identification of need especially in relation to mental health. Parents suggested that individually targeted health education for children with learning disabilities would be welcome.

No specific information on access to health promotion or education was identified for people from different ethnic minorities, for men and women on issues specific to them, or for other special communities, which may include those living in 'campus-style' or forensic accommodation. These are all identifiable subgroups of people with learning disabilities whose needs or living conditions signal potential issues for the provision of this type of service.

***3.2 Identification of health need***

Identification of need is perhaps the first stumbling-block to health care for people with learning disabilities. Learning disability affects the ability to recognise and interpret signals not only from the outside world but also from the inner world of the person's own body. It is not possible to access health care without recognition of need. This section therefore examines the evidence on whether health need is identified in a timely manner so that appropriate access to health services may be sought.

As identification of health need in people with learning disabilities may be detected by a number of individuals (private and professional), consideration of the literature will look at these individuals separately: people with learning disabilities themselves; family and paid (residential) carers; community service providers (such as staff in day provision and school nurses); 'continuing' health care staff; and 'other' service-based reviews (including residential facility medicals and special educational need reviews).

### **3.2.1 Identification of need by people with learning disabilities**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8478	Gilbert-McLeod, C.A., Craig, K.D., Rocha, E.M. and Mathias, M.D. 2000. 'Everyday pain responses in children with and without developmental delays', <i>Journal of Pediatric Psychology</i> 25(5): 301-8	Quantitative	Pre-school	Mild/moderate	2
211	Purcell, M., Morris, I., and McConkey, R. 1999. 'Staff perceptions of the communicative competence of adult persons with intellectual disabilities', <i>British Journal of Developmental Disabilities</i> 45(88): 16-25	Quantitative	Adult	All	3
8383	Speechley, M. 2002. <i>Adults with profound and multiple learning disabilities: perceived and real obstacles to accessing vision testing services</i> , Dissertation. Manchester: University of Manchester	Quantitative	Adult	Profound	3
<u>7943</u>	Maternity Alliance. 1999. <i>Maternity Services for Women with Learning Difficulties: A report of a partnership of midwives, community nurses and parents</i> . London: Maternity Alliance	Qualitative	Adult	NR	4

The literature addressing the issue of identification of need by people with learning disabilities themselves was small and varied widely in quality.

#### **Children**

The only study on identification of health need in relation to children with learning disabilities<sup>8478</sup> focused on their reaction to pain. This sound study of children with and without developmental delays reported that those with developmental delay showed less vigorous responses to comparable pain events. They also instigated fewer help-seeking activities even though they tended to be in closer proximity to adults. The only pain-related behaviour to increase with age for these children was the anger response. It appeared that the children were perhaps developing the ability to signal pain but using different behaviours from normally developing children.

***Adults/older adults***

A study of the challenges of providing optometry to people with profound and multiple disabilities suggested that these individuals signalled unspecified need by changes in routine behaviour<sup>8383</sup>. However, a separate study<sup>211</sup> suggested that even the most committed and motivated of staff have difficulty in identifying non-verbal signals. Touch was the only signal reliably identified by carers in a naturalistic observational study. Other non-verbal signals such as gestures, head nods and facial expressions remained largely unobserved. Although the evidence is limited, it suggests that unless behaviour change is substantial and outward in its effect people with severe and profound learning disabilities will be unable to signal need.

Another issue raised in the literature affected more able women with learning disabilities. This study, not 'good' in terms of academic rigour but nevertheless thought-provoking, investigated the barriers to women accessing maternity services<sup>7943</sup>. Women who took part in this study suggested that apprehension about having to undergo tests and answer difficult questions, as well as negative attitudes from service staff in relation to the pregnancy, affected their willingness to access services. The women also commented that lack of support and negative attitudes towards their ability to cope also made them less likely to seek antenatal care.

These studies indicate the importance of the responsiveness of carers and health staff to people with learning disabilities needing to access health services. They also signal the different nature of the challenge that identifying need, as a stage of self-referral, poses for people with more or less severe learning disabilities. The limited evidence on people with severe learning disabilities suggested they may be unable to communicate their distress even where they are aware of it. More evidence is needed on the willingness of people with mild learning disabilities to access services, particularly their perceptions of the attitudes of service providers towards them.

We came across no studies that directly examined self-referral, or the consequences of reporting/indicating poor health to care staff or parents by people with learning disabilities who had communication skills. We found no exploration of the effects of ageing, or cultural or language differences on communication of health need in the literature.

**Issues raised in consultations**

Gaps in research were identified in relation to:

- identifying multiple health needs
- communication with carers about health need.

Discussion with paid carers highlighted issues illustrating that even where the person is able to communicate verbally, problems can be encountered in identifying and communicating about multiple health problems. For example, in the case of a man who had experienced multiple health needs, the more serious need (affecting internal organs) was not addressed because the man was more concerned with a problem that affected his mobility (external in effect). Unfortunately this man died of the unattended problem. Paid carers also suggested that people with learning disabilities sometimes do not bring health problems to the attention of carers because they are frightened of the consequences. Medical appointments, testing and intervention can be construed as punishment where they are unpleasant and, in the absence of appreciation of the benefits to be gained from enduring such treatment in the short term, may deter an individual from seeking health care.

These two points suggest a need for research into how more able people with learning disabilities communicate about their health status and their views on approaching health services for care.

**3.2.2 Identification of health needs by parents and carers**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<b>2804</b>	Beange, H., McElduff, A., and Baker, W. 1995. 'Medical disorders of adults with mental retardation: a population study', <i>American Journal of Mental Retardation</i> 99(6): 595-604	Quantitative	Adult	All	1
299	Moss, S. and Patel, P. 1993. 'The prevalence of mental illness in people with intellectual disability over 50 years of age, and the diagnostic importance of information from carers', <i>Irish Journal of Psychology</i> 14(1): 110-29	Quantitative	Older adult (50+)	All	2
906	Howells, G. 1986. 'Are the medical needs of mentally-handicapped adults being met?', <i>Journal of the Royal College of General Practitioners</i> 36(291): 449-53	Quantitative	Adult	All	2

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<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
2837	Evenhuis, H.M. 1995. 'Medical aspects of ageing in a population with intellectual disability: II. Hearing impairment', <i>Journal of Intellectual Disability Research</i> 39: 27–33	Quantitative	Older Adult (60+)	Mild, moderate, severe	2
5357	Thornton, C. 1999. 'Effective health care for people with learning disabilities: a formal carers' perspective', <i>Journal of Psychiatric &amp; Mental Health Nursing</i> 6: 383–90	Qualitative	Adult	All	2
8350	Donovan, J. 2002. 'Learning disability nurses' experiences of being with clients who may be in pain', <i>Journal of Advanced Nursing</i> 38: 458–66	Qualitative	NR	Severe	2
8359	Kerr, A.M, McCulloch, D., Oliver, K., McLean, B., Coleman, E., Law, T. <i>et al.</i> 2003. 'Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports', <i>Journal of Intellectual Disability Research</i> 47: 134–45	Quantitative	NR	All	2
8478	Gilbert-McLeod, C.A., Craig, K.D., Rocha, E.M. and Mathias, M.D. 2000. 'Everyday pain responses in children with and without developmental delays', <i>Journal of Pediatric Psychology</i> 25: 301–8	Quantitative	Pre-school	mild/moderate	2
211	Purcell, M., Morris, I. and McConkey, R. 1999. 'Staff perceptions of the communicative competence of adult persons with intellectual disabilities', <i>British Journal of Developmental Disabilities</i> 45: 16–25	Quantitative	Adult	All	3
575	Nadler, A., Lewinstein, E., and Rahav, G. 1991. 'Acceptance of mental-retardation and help-seeking by mothers and fathers of children with mental-retardation', <i>Mental Retardation</i> 29(1): 17–23	Quantitative	Primary school	Mild/moderate	3
850	Bambrick, M. and Roberts, G.E. 1991. 'The sterilization of people with a mental handicap – the views of parents', <i>Journal of Mental Deficiency Research</i> 35: 353–63	Quantitative	Adolescent/young adult	Severe	3
3401	Wilson, D.N. and Haire, A. 1990. 'Health care screening for people with mental handicap living in the community', <i>British Medical Journal</i> 301: 1379–81	Quantitative	Adult	All	4

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<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
4405	Munden, A.C. and Perry, D.W. 2002. 'Symptoms of depression in people with learning disabilities: Knowledge of various members of the multidisciplinary team involved in the care and assessment of challenging behaviour', <i>Journal of Learning Disabilities</i> 6: 13–22	Quantitative	Older adult (60+)	All	3
5317	Sham, S. 1996. 'Reaching Chinese children with learning disabilities in greater Manchester', <i>British Journal of Learning Disabilities</i> 24: 104–9	Qualitative	Adolescent (to 18)	All	3
5646	Langan, J., Whitfield, M., Russell, O. 1994. 'Paid and unpaid carers: their role in and satisfaction with primary health care for people with learning disabilities', <i>Health &amp; Social Care in the Community</i> 2: 357–65	Quantitative	Adult	All	3
7785	Rawlinson, S.R. 2001. 'The dental and oral care needs of adults with a learning disability living in a rural community', <i>Journal of Learning Disabilities</i> 5: 133–56	Quantitative	Adult	All	3
7856	Singh, P. 1997. <i>Prescription for change: a Mencap report on the role of GPs and carers in the provision of primary care for people with learning disabilities</i> . London: Mencap	Quantitative	NR	NR	3
8352	Roy, M., Corbett, J., Newton, J. and Roy, A. 1993. 'Referrals of persons with a learning disability (mental handicap) for fertility regulation: A regional survey', <i>Journal of Obstetrics &amp; Gynaecology</i> 13: 361–4	Quantitative	Adult	All	3
8383	Speechley, M. 2002. <i>Adults with profound and multiple learning disabilities: perceived and real obstacles to accessing vision testing services</i> , dissertation. Manchester, University of Manchester	Quantitative	Adult	Profound	3
8401	Rudkin, A., Heason, C. and Rowe, D. 1999. 'An audit of health monitoring in an adult population with profound learning disability', <i>Journal of Clinical Excellence</i> 1: 137–40	Quantitative	Adult	Profound	3
8503	Carter, B., McArthur, E. and Cunliffe, M. 2002. 'Dealing with uncertainty: parental assessment of pain in their children with profound special needs', <i>Journal of Advanced Nursing</i> 38: 449–57	Qualitative	NR	Profound	3

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<u>7849</u>	Bristol & District Community Health Council. 1998. <i>Is anybody listening to us? Perceptions of healthcare from PLD and their carers</i> . Bristol: Bristol and District Community Health Council	Qualitative	NR	NR	4
<u>8045</u>	Ashman, A.F. and Suttie, S. 1996. 'The medical and health status of older people with mental retardation in Australia', <i>Journal of Applied Gerontology</i> 15: 57–72	Quantitative	Older Adult (60+)	All	4

A quite substantial literature was identified touching on the role of family and paid carers in the identification of health need. However this aspect of access was not the primary focus of many. Approximately half the studies were rigorous and the majority of the remainder less rigorous.

### **Children**

Where expression of distress is muted<sup>8478</sup> the chances of need being overlooked or underestimated would appear to be increased. In one study<sup>8503</sup> parents of profoundly disabled children expressed the view that their child had 'learned to live with pain'. In these circumstances parents had to fall back on guesswork in dealing with the distress of their children. None had been taught how to assess their child's pain. Parents' opinions of GP services suggested that they were treated with sympathy and concern but that optimal pain management was obtained from specialist pain clinics. These two studies together suggest that children may not be accessing health care services in a timely fashion and be suffering due to the difficulties in identifying distress signals or their cause.

A qualitative study was identified which looked at service access, including health services, for children with learning disabilities whose parents had immigrated to the UK from Hong Kong<sup>5317</sup>. Two main barriers to service use were identified: communication problems and cultural beliefs. The author suggests that cultural differences in understanding and interpreting issues of health and illness can lead to long-term misunderstanding and inappropriate action by parents. Parents were reluctant to accept, or did not understand, the diagnoses of Western doctors or specialists. They found it hard to accept the idea of permanent impairment and invested a great deal of effort and expense in a search for a 'cure' via traditional routes. This evidence suggests that some Chinese families may not seek appropriate and timely health care for their child with learning disabilities, falling back instead on their own resources. A limitation with this study, however, was the lack of information on how typical the study families were of the population of Chinese people in the region (North West) or the UK.

An investigation into parental help-seeking behaviours in relation to a number of scenarios, including health<sup>575</sup>, suggested that parents with higher levels of educational attainment tended to be more willing to seek out professional help. Parental gender differences in willingness to seek help (with mother less willing) were confounded due to failure to control for level of educational attainment. However, the study does not explore the reasoning behind decisions to seek or not seek professional help – information that would have provided depth to what is otherwise a purely descriptive study.

### ***Adults***

Many studies assessing the medical needs of adults with learning disabilities have pointed to the difficulties experienced by paid and family carers in identifying signs of health need in those they care for<sup>211 2804 5646 8359 8383</sup> and the reluctance to seek help for 'trivial' complaints<sup>906 7785</sup>. Eighty-seven per cent of family and paid carers<sup>7856</sup> in one study reported that they undertook health monitoring. However, even where the role of health monitor is acknowledged, identification of health need is not an easy task. In a study of health monitoring for adults with profound learning disabilities<sup>8401 5357</sup>, an audit found health care had been delivered on an 'ad hoc basis'. Checks involving medication review, sight testing, hearing testing, dental check-up, continence and weight checks were of variable standard. No individual had received all checks to an adequate standard. The authors comment on the poor quality of feedback to carers from testing, severely inhibiting adequate responses to need.

The value of long-term trusting relationships between people with learning disabilities and their paid carers or family members has been acknowledged to facilitate identification of health need<sup>8350</sup>, but studies on unmet need suggest this has proved insufficient to ensure consistent and reliable identification. Long-term relationships may make changes from 'normal' health status easier to identify in the face of ongoing communication difficulties<sup>211</sup>, but they can make other needs harder to spot<sup>8359</sup>, particularly those where deterioration is very gradual and over the longer term such as in sight and hearing. Where informal carers do identify issues one study, methodologically poor especially in the lack of specificity about the age group and ability level of the individuals it addressed, pointed out that whether services were obtained relied to a great extent on the assertiveness of the carer<sup>7849</sup>.

Access to sight and hearing tests may also be limited by assumptions on the behalf of carers that such testing is not necessary<sup>3401</sup>, for example, for people who do not read or write, or interact with others in their daily lives, as commented by care staff in one study, which was methodologically poor<sup>8045</sup>. In a study of vision testing among people with severe and profound learning disabilities, carers acknowledged that it was within their role to identify problems with vision and/or suggest sight testing, however more than 4 out of 5

people had not had a sight test since leaving school (average age 30 at the time of the study)<sup>8383</sup>. Another study<sup>5646</sup> found that two-thirds of carers (paid and family) failed to bring health promotion issues to the attention of their GP. Some carers who expressed dissatisfaction with the frequency of medical reviews still failed to act. A study on dental health<sup>7785</sup> found that a small percentage of people with learning disabilities were not registered with a dentist at all. Dental health was reported as having minor importance by family and paid carers, and older people with few or no teeth were assumed not to need a dentist. Pain was the stated criterion for dental intervention.

One issue that is extensively debated in the literature is accessing health services to obtain sterilization for people with learning disabilities for the purpose of fertility regulation. The debate centres around who may give consent to such a procedure and in what circumstances. These papers are not reviewed here. However, it was considered necessary to draw attention to this debate here because, where sterilization is sought, parents are often attempting to gain access to services on behalf of (usually but not exclusively) their daughters for a procedure unrelated to health need<sup>8352</sup>. Many parents appear to feel that they alone, or in conjunction with a doctor familiar with the families' circumstances, should have the power to consent to non-medical sterilization<sup>850</sup>.

### ***Older adults***

Problems identifying deteriorating eyesight and hearing become increasingly pertinent for people with learning disabilities in older age, in whom 33 per cent of 60–70 year olds and 70 per cent of people aged 71 or over have been found to have bilateral hearing loss<sup>2837</sup>. Although we identified no study specifically exploring access to audiology and optometry for this age group, it is likely that much of the unmet need identified in studies targeting all people with learning disabilities on a register or using a service will be accounted for in this group.

Studies on the presence of mental ill health in older people with learning disabilities have also found significant unmet need<sup>299 4405</sup>. There is agreement that carers have difficulties recognising the symptoms of mental illness, including depression and dementia; however, one study reported that carers were aware of symptoms but tended not to recognise them as indicating mental illness<sup>299</sup>.

Literature was a more extensive on the role of third parties in identifying health need than that on identification by individuals themselves. It provides evidence for the crucial role of third parties in the identification of health need in people with learning disabilities. However, it also seems to indicate that despite third-party efforts some health needs remain undetected. More evidence is also needed on the impact of cultural beliefs on the perceived need to access services.

**Issues raised in consultations**

Gaps in research were identified in relation to:

- decision making by parents and paid carers about accessing health care
- the influence of cross-gender carer/cared-for issues on access to health care.

Parents discussed the very difficult judgements they face about whether to approach their GP. Changes in behaviour or mood may have no particular significance in terms of health and result in unnecessary trips to see the GP, but failure to act may mean ignoring significant ill health. Studies are needed on the processes involved in parental decision making with regard to approaches to health care.

A contact from the National Development Team suggested that for adults, carer/cared-for gender conflicts could be a barrier to health care. This was thought to be particularly relevant to men with learning disabilities being cared for by women. These men may not wish to bring a problem of a sensitive nature to the attention of their female carer. Additionally, it was suggested that female carers may be unaware of male health issues and that this may mean some health problems are overlooked. There is a need for research in this area.

**3.2.3 Identification of need by community service providers**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<u>4060</u>	Rustia, J., Hartley, R., Hansen, G., Schulte, D. and Spielman, L. 1984. 'Redefinition of school nursing practice: integrating the developmentally disabled', <i>Journal of School Health</i> 54: 58–62	Quantitative	primary–adolescent	mild/moderate	4

'Home' carers are often not the only people in day-to-day contact with a person with learning disabilities. Carers in day or other settings regularly care for individuals during their daytime activities. There is also potential here to identify needs that may not be apparent in the home setting. There was no UK evidence base on the role of community service providers in identifying health need. Wider specific searching revealed only one US study, of poor quality, related to the topic.

**Children**

The study identified looked at the role of mainstream school nurses in accessing health care and was from the US<sup>4060</sup>. The study was poor in terms of academic rigour; however, we considered that this issue needed to be raised within the review because it was raised in our

consultations. The study suggested that parents shared health related information with school nurses, who also initiated referrals based on the concerns of teaching staff. However, nurses tended not to share the knowledge they gained with other staff (from the viewpoint of the study to the detriment of teaching and learning). The study suggested school nurses had a role in referral but did not address whether they also had a role in identifying need. Studies are needed on the role of school nurses in special schools or mainstream schools in accessing health care for children with learning disabilities in the UK.

***Adults/older adults***

No papers were identified that looked at identification of health need by community service providers. The role of social service personnel responsible for delivery of occupational programmes in identification of need is unclear. Given the support in the literature for the efficacy of long-term relationships in identification of health need, it is less likely that these will be identified in day settings unless they are acute and unambiguous. However, problems may become apparent in day settings that are not an issue at home. The role of staff in day settings in identification of need therefore requires investigation.

***Issues raised in consultations***

Gaps in research were identified in relation to:

- the role of school nurses in identifying health need in children with learning disabilities
- the roles of education and social care staff in identifying health need.

Our discussions with parents of children with learning disabilities highlighted implications for access to health care in current policies towards the inclusion of children with learning disabilities in mainstream schools. Although parents approved of this move for many children, notably those less severely affected by learning disabilities, they were concerned about the effect this would have on access to health care currently facilitated by the school nurse. These nurses are often based on school premises full time and provide referrals for children to speech and language therapy and physiotherapy, among other services. In mainstream schools a nurse may visit for half a day per week and will cover several schools in a locality. It is doubtful that they are currently equipped to provide the type of service that has been suggested is provided in special schools. This appears to be an area where more information is needed on the effectiveness, appropriateness and remit of school nurses in accessing health care.

Parents also raised the issue of the part played by other service providers in the identification of need in their children. These included transport staff who may have care of the children for up to three hours per day, due to extended journeys to school when picking up

children from all the surrounding area. They queried the role of respite care providers, many of whom now provide care on a 'home-from-home' basis, in identifying need and accessing health care. Children spend varying lengths of time in respite care, from a weekend to a fortnight, and although respite carers are at liberty to seek A&E care at need, their capability to identify and report other signs and symptoms are unclear, as is the amount of training they have received to take on the role.

### **3.2.4 Identification of health need by 'continuing' care staff**

No evidence base was identified on identification of need by staff in secondary health care settings.

Gaps in research were identified in relation to:

- Identification of additional health needs by secondary, or 'continuing' health care staff including community learning disability teams (CLDTs).

Given the increased likelihood that people with learning disabilities, adults and children, will be in contact with services providing continuing health care, for example for epilepsy, speech and language therapy, physiotherapy or mental health care, the opportunities for identification of additional health needs will also be increased. No study covered this issue. This was not an issue raised within discussion groups. To our knowledge, only community learning disability teams are likely to have a recognised role in identification of health need.

### **3.2.5 Identification of need through 'other' service reviews**

No evidence was found on the role of non-health service care reviews in the identification of need.

#### ***Issues raised in consultations***

Gaps in research were identified in relation to:

- the role of residential homes' medical assessments in identifying health need
- the place of the Special Educational Need review in identifying additional health needs.

In the course of our consultation with family and paid carers it became apparent that identification of need may occur during a residential facility's own health check programme or may be flagged up during reviews of Special Educational Need statements. Paid care staff reported that the facility's annual check was very basic and therefore limited in the type of problem it was likely to identify. Parents reported that health issues were sometimes raised during Special Educational Need reviews due to a lack of any other forum to address them in a co-ordinated way. There does not appear to be any literature on the role of these reviews in access to health care, even though they may potentially provide an important route to care.

### **3.3 Organisational determinants of access to health care**

The organisational determinants are those that determine whether an individual 'has access' to health care. They combine aspects of the availability and appropriateness of services and the availability and effectiveness of the carer or advocate who enables the person with learning disabilities to access health care. Proactive screening and surveillance programmes are also considered a means of facilitating access to health care and for that reason they are considered in this part of the model. This section will explore the evidence on whether people with learning disabilities 'have access' to a range of health care services.

As the availability and appropriateness of different types of service will vary, they are considered separately below. It is unsurprising that a great deal of the literature concentrated on the availability and appropriateness of GP services, since these are most frequently sought by the general population, including people with learning disabilities. However because people with learning disabilities tend to have additional health needs the availability and appropriateness of specialist health services are also of particular concern.

### **3.3.1 Availability and appropriateness of GP services**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
906	Howells, G. 1986. 'Are the medical needs of mentally-handicapped adults being met?', <i>Journal of the Royal College of General Practitioners</i> 36: 449–53	Quantitative	Adult	All	2
5357	Thornton, C. 1999. 'Effective health care for people with learning disabilities: a formal carers' perspective', <i>Journal of Psychiatric &amp; Mental Health Nursing</i> 6: 383–90	Qualitative	Adult	All	2
8175	Steele, B. and Sergison, M. 2001. <i>Improving the Quality of Life of Ethnic Minority Children with Learning Disabilities</i> . Huddersfield: Huddersfield NHS Trust	Mixed	Adolescent (to 18)	All	2
2649	Thornton, C. 1996. 'A focus group inquiry into the perceptions of primary health care teams and the provision of health care for adults with a learning disability living in the community', <i>Journal of Advanced Nursing</i> 23: 1168–76	Qualitative	Adult	All	2
5317	Sham, S. 1996. 'Reaching Chinese children with learning disabilities in greater Manchester', <i>British Journal of Learning Disabilities</i> 24: 104–9	Qualitative	Adolescent (to 18)	All	3
7856	Singh, P. 1997. <i>Prescription for Change: A Mencap report on the role of GPs and carers in the provision of primary care for people with learning disabilities</i> . London: Mencap	Quantitative	NR	NR	3
8193	Freeney, M., Cook, R., Hale, B. and Duckworth, S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8228	Sense. 2001. <i>Who Cares? Access to healthcare for deafblind people. A 'Yes to Access' Campaign Report.</i> London: Sense	Report	NR	NR	3
8255	McCarthy, M. 2002. 'Responses to women with learning disabilities as they go through the menopause', <i>Tizard Learning Disability Review</i> 7: 4-12	Quantitative	Adult	NR	3

A moderate evidence base was found on the availability and appropriateness of GP services. The quality was a mix of rigorous and less rigorous studies that addressed a range of issues.

### **Children**

Two studies addressed the needs of children, and given the global need for parental accompaniment and advocacy on behalf of their children this is not a particular issue for children with learning disabilities. However, many of the studies addressing the needs of adults will apply equally to children. The studies identified highlighted the additional problems families from ethnic minorities experience as a result of language differences<sup>8175 5317</sup>. Forty-six per cent of families interviewed noted inconsistencies in the extent to which interpreters and link workers were available during consultations and this remained an ongoing problem for them<sup>8175</sup>. In a separate study of access to services for children whose parents had immigrated from Hong Kong, communication within consultations also proved difficult. The translation service often proved inadequate because the translator did not always understand the content of what was to be communicated<sup>5317</sup>.

### **Adults/older adults**

A problem commonly affecting access for both children and adults with learning disabilities was related to use of the waiting room. Parents, embarrassed by the behaviour of their son or daughter, may think twice about whether to seek advice<sup>906</sup>. Parents and carers are also crucial to facilitating communication between the GP and the patient<sup>5357 7856</sup>. It has been suggested that low expectations and bad past experiences may also affect willingness to access care<sup>7856</sup>.

One comprehensive survey of the accessibility of health care premises<sup>8193</sup> identified difficulties with signage and unhelpful attitudes from reception staff as barriers to access. The authors reported a widespread perception that GPs may refuse to take a person with learning disability on to their list because of the disproportionate amount of time taken to treat them. There was little support found

among the wider literature for this position, although one study found that two out of three GP practices surveyed had considered that they might need to restrict the number of people with learning disabilities on their registers in the interests of the practice as a whole, because they felt that the remuneration was insufficient to work with this group<sup>2649</sup>.

An investigative report into access to health care for deaf-blind people<sup>8228</sup>, including people with additional learning disabilities, found that a significant minority avoided visiting their GP because communication was too difficult and they were often uncertain whether aids were available to facilitate communication. The report suggested that there was insufficient access to aids, such as loop systems at reception desks and in consulting rooms, and that information was often sent out in inaccessible formats. The implications of the results of these studies suggest that insufficient thought is given to the information needs of people with literacy and sensory difficulties or impairments in addition to their learning disabilities, making accessing services an anxiety-provoking and frustrating experience.

One further study identified a lack of availability of a service for women with learning disabilities undergoing the menopause<sup>8255</sup>. This study, though suffering a low response rate from participants, suggested that less than half of general practices offered a specialist menopause service for women with learning disabilities. However, it also found that less than half of GPs contacted had treated a woman with learning disabilities and most of these had seen only one or two women. This suggests low demand for such a specialist service within any GP practice but does not necessarily preclude facilitation for these women to attend mainstream primary care.

### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- the availability of accessible information on health services for people with learning disabilities
- the role of 'front-line' staff in facilitating access to health services
- the influence of parents and paid carers on seeking health care
- the influence of staffing issues on seeking health care for people with learning disabilities living in residential care
- access to mainstream general practice services for people living in segregated settings
- the role of parents and paid carers in facilitating effective communication during health interviews.

Accessible information is perhaps one of the most fundamental requirements in accessing services. Patients cannot access services they do not know exist; however, no studies looking at this aspect of access were identified.

Parents' comments highlighted issues, not evident in the literature, concerning contacts with reception staff at GP practices that may facilitate access to the service. They suggested that familiarity with personnel in the practice was very helpful in obtaining speedy and appropriate access to the GP. A receptionist who knows the child and family's circumstances is better equipped to appreciate the need for a suitable appointment for the child. Parents pointed out, however, that this was much more difficult in large practices because of the greater number of reception staff involved.

A representative from the Disability Rights Commission pointed out that parents and other third parties involved in accessing health care for people with learning disabilities could potentially empower individuals to access services. However, there was considerable comment from a number of sources about the barriers that family carer involvement can introduce into health care. Paid carers and the representative of the Disability Rights Commission gave examples of parents refusing to allow access to health care for their son or daughter based on fear of the consequences, considered to be due to guilt or self-blame regarding the health problem, or bad experiences with health services in the past. Paid carers also expressed their own fears in seeking health care for older people with learning disabilities. In these circumstances subsequent diagnosis of dementia may result in the person losing their home of many years, to the great sadness of their friends and carers. Paid carers also exerted an influence over which practice the residents were registered with, so that if they were dissatisfied with a practice they would change either to a different GP within the practice, or to a different practice. Once an effective practitioner was discovered, other residents would be transferred to this GP's list. The extent to which third parties empower or inhibit access to health care is an area needing further research.

Organisational aspects of access to GP services were more complex for the adults living in a residential facility. Adults with learning disabilities who lived in community housing used a local GP practice in the same way as the rest of the community. However, providing accompaniment to appointments was problematic for community carers. One carer stated that she had, on occasions, to take a resident along to another person's GP appointment because there was no one else to look after them. In pursuit of confidentiality for the person with a health concern, the accompanying resident was left to sit outside the surgery door while the carer took the person in to their appointment. She pointed out that this situation was not ideal and that her concentration during the consultation was limited because of concerns for the well-being of the person left alone in the corridor.

People with learning disabilities living on a residential campus received a different service. For them the facility had a long-standing arrangement with a local practice for one of two GPs to visit the site twice a week on regular days. This arrangement did not preclude visits to the practice at other times; however, the implications for staff time

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and transportation are likely to have exerted a powerful influence on decisions to wait for the next on-site surgery. Another difference between the campus and community residencies was the availability of a fully qualified nurse on site 24 hours a day. This nurse provided triage so that some health problems could be dealt with more promptly. Conversely, people requiring access to GP attention could face delays as a consequence of the facility's procedures for accessing health care. Paid carers commented that whether to seek NHS health care was a team decision.

Paid carers also discussed the issue of using agency or bank staff to accompany a person with learning disability to health appointments. They described situations in which this had occurred in the past because of a shortage of regular staff to perform this task. They stated that these temporary staff were unable to support the person as a regular carer would, they often did not know the person very well, and they were ignorant of their medical history. They were also less familiar with the communication style of the person they accompanied and therefore could not facilitate the consultation process. They suggested that this was an unhelpful practice.

A representative from the National Development Team also highlighted the less than optimum experience of other people with learning disabilities living on 'campuses' run by a variety of organisations. Access to general health care for people with learning disabilities living in segregated settings, for example nursing homes or medium secure units, is likely to vary from that experienced by the general population. We identified no studies looking specifically at access to health care for people living in special circumstances.

### 3.3.2 Availability and appropriateness of dentist/optician services

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<b>1841</b>	Tiller, S., Wilson, K. I. and Gallagher, J.E. 2001. 'Oral health status and dental service use of adults with learning disabilities living in residential institutions and in the community' <i>Community Dental Health</i> 18:167-71	Quantitative	Adult	Severe/ profound	1
195	Leahy, J., Lennon, M.A. 1986. 'The organization of dental care for school children with severe mental handicap', <i>Community Dental Health</i> 3: 53-9	Quantitative	Primary school	Severe/ profound	3
7785	Rawlinson, S.R. 2001. 'The dental and oral care needs of adults with a learning disability living in a rural community', <i>Journal of Learning Disabilities</i> 5: 133-56	Quantitative	Adult	All	3
7921	Lyon, J.W. 1997. <i>The oral health of adults with learning disabilities living within the community in north Warwickshire who do not access the community dental service</i> , thesis, Master of Dental Science. Birmingham: University of Birmingham	Quantitative	Adult	Moderate	3
8193	Freeney, M., Cook, R., Hale, B. and Duckworth, S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3

This small evidence base comprises only one highly rigorous study but this study is supported by other moderate studies, some of which recorded similar findings.

Dental services are available for people with learning disabilities from three sources, general dental practices (GDP) otherwise known as high-street dentists, community dental services (CDS) which tend to be based in community clinics, and hospital dental services. The papers reviewed covered this range of services.

#### **Children**

Only one study investigated the organization of dental care for children. The authors found that children with severe learning disabilities tended to access GDS and CDS for dental checks<sup>195</sup>.

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However less than half, on average, received regular care. In families where a sibling accessed regular dental care, although their brother or sister with learning disabilities did not, the main barrier was found to be maternal anxiety about using the service. Despite placing high importance on dental health for their child, dental health care was avoided because it was considered it would be an unpleasant experience for the child; because there could be difficulties in the waiting room causing embarrassment to the parent; and because of the need to explain the handicap. It is entirely possible that these barriers also exist for adults with severe learning disabilities.

### ***Adults/older adults***

Adults with severe or profound learning disabilities living in the community (informal care) were found, in a detailed study, to have comparatively higher levels of untreated decay than people living in residential accommodation<sup>1841</sup>. Community participants reported being less likely to access dental care on a regular basis and to be more likely to have no dentist and only to seek care when having trouble. Two further studies found that 70–80 per cent of adults living in informal and formal care were registered with a dentist<sup>7785 7921</sup>. In one study almost two-thirds of those registered were reported as using CDS<sup>7785</sup>; however, less than half of carers in another study were aware of the existence of CDS<sup>7921</sup>. Family and paid carers reported NHS dentists hard to find and some reported that the person they cared for had been refused registration with a dentist (GDS) on the grounds of a medical condition or challenging behaviour. The registration rules also caused difficulties accessing dental care because registrations lapse if the service is not accessed for fifteen months. Carers saw themselves as responsible for making and keeping appointments, as well as accompanying the person to their appointment. However, if appointments were not kept the person could lose their registration because they had not accessed the service. They could then find themselves unable to re-register with the same dentist if their list was full. Among those using community dental services, infrequent surgeries and inflexibility in service provision were found to make access awkward or insufficient.

No literature was identified on whether people with learning disabilities access optician services with the same frequency as non-disabled people.

The same problems of physical access, poor signage and unhelpful attitudes from reception staff were found among dental premises surveyed as had been identified in general practice<sup>8193</sup>. However, in this instance the study noted above<sup>7785</sup> supports the position that some people with learning disabilities may be refused registration with some dental practices.

***Issues from consultations***

Gaps in the literature were identified in relation to:

- the influence of challenging behaviour on access to mainstream health services
- parent and paid carer roles in accessing health services for people living in formal care
- the consequences for practitioners of providing services to larger numbers of people with learning disabilities
- the availability of mainstream optometry services for people with learning disabilities.

Parents commented that their children with severe or profound learning disabilities had challenging behaviour and were therefore referred through school to the 'Special Needs' dentist. This raises the question about access to this type of service for children with learning disabilities who attend mainstream schooling.

Parents also reported that their children were not able to use high-street opticians, also due to challenging behaviour. Discussions with young people with learning disabilities revealed that several were still accessing the hospital eye clinics they had started attending as children. For these people, parents still facilitated access, organising and transporting their son or daughter to and from appointments. This practice may well ease the difficulties for paid staff of accompanying a person to their appointment while still having to make provision for the care of other people in the setting. However, it would appear to make co-ordination and overview of health matters more complex.

Paid carers reported that the people they cared for accessed local dental services but that some practitioners were more skilled than others. In these cases carers tended to 'vote with their feet' and promote registration with skilled practitioners for all the people with learning disabilities they were in contact with. This practice will have repercussions for dentists who are more skilled, resulting in a practice list with a significant number of patients with more complex needs requiring longer appointment times.

### 3.3.3 Availability and appropriateness of population health screening

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<b>7920</b>	Nightingale, C.E. 1997. <i>Issues of access to health services for people with learning disabilities: a case study of cervical screening</i> . PhD thesis. Cambridge: Anglia Polytechnic University	Qualitative	Adult	NR	1
2649	Thornton, C. 1996. 'A focus group inquiry into the perceptions of primary health care teams and the provision of health care for adults with a learning disability living in the community', <i>Journal of Advanced Nursing</i> 23: 1168–76	Qualitative	Adult	All	2
1602	Davies, N. and Duff, M. 2001. 'Breast cancer screening for older women with intellectual disability living in community group homes', <i>Journal of Intellectual Disability Research</i> 45: 253–7	Quantitative	Older adult (50+)	All	3
1974	Broughton, S. and Thomson, K. 'Women with learning disabilities: risk behaviours and experiences of the cervical smear test', <i>Journal of Advanced Nursing</i> 32: 905–12	Mixed	Adult	Moderate	3
4621	Pearson, V., Davis, C., Ruoff, C. and Dyer, J. 1998. 'Only one quarter of women with learning disability in Exeter have cervical screening', <i>British Medical Journal</i> 316: 1979	Quantitative	Adult	All	3
8098	Hogg, J., Northfield, J. and Turnbull, J. 2001. <i>Cancer and People with Learning Disabilities: The evidence from published studies and experiences from cancer services</i> . Kidderminster: BILD	Qualitative	All	All	3
8155	Kerr, M.P., Richards, D. and Glover, G. 1996. 'Primary care for people with an intellectual disability – a group practice survey', <i>Journal of Applied Research in Intellectual Disabilities</i> 9: 347–52	Quantitative	All	All	3
8193	Freeney, M., Cook, R., Hale, B. and Duckworth, S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3

This evidence based contained two rigorous or better studies relating to cervical screening for women with learning disabilities. However,

the remaining evidence relating to cancer and other types of screening was less rigorous in quality.

***Adults/older adults***

The literature has identified problems around accepted practice on access to screening<sup>8098</sup>. A dearth of specific materials for people with learning disabilities on cancer, and a lack of knowledge, information<sup>8193</sup> and adequate planning for visits, constitute barriers to screening<sup>8098</sup>.

One of the most contentious issues in the literature was around access to cervical and breast cancer screening among women with learning disabilities. An audit of medical records in one health district found that less than one in four women with learning disabilities had undergone a smear test compared to more than four out of five women in the general population<sup>4621 8155</sup>.

From one extensive investigation into cervical screening provision a 'defensive model' of screening provision emerged<sup>7920</sup>. National health policy on cervical screening included women with learning disabilities by implication but general practices were able to place their own interpretation on it locally. Attitudes and assumptions among health professionals to the policy, and to women with learning disabilities, generally resulted in their not being invited to screening. The apparent motivation to protect vulnerable women from an intrusive intervention actually served to protect the service from having to work with challenging patients. The potential of any screening service to identify early signs of disease in the people it serves will be severely undermined if some of those people are not invited to attend. The psychological/emotional issues associated with cervical screening were found to lead in part to a poor level of health education and promotion generally, and a wish to 'protect' the individual. The research concluded that the service was designed around the needs of the practice and not those of people with learning disabilities or others with poor literacy<sup>7920</sup>. In contrast, another study into the attitudes of primary care staff to health care provision for people with learning disabilities found all those surveyed were positive that invitations for smear tests were sent out automatically to women with learning disabilities<sup>2649</sup>. Invitations sent out in this way enable the women to enlist the help of a carer to facilitate the screening process. However, other practice-based screening was only advertised on practice notice boards. Patients were therefore required to read notices and request an appointment for screening. This put those with literacy problems at a disadvantage.

Similarly, in relation to mammography screening, studies have found a lower percentage of women with learning disabilities included in screening. They found women with learning disabilities being omitted from GP lists of registered patients eligible for mammography screening<sup>1602 1974</sup>. These researchers suggest that such omissions may

be due to GP assumptions regarding the appropriateness of the service for these women, reflecting the findings of the study noted above<sup>7920</sup>. However, other evidence has suggested that these women may, in fact, be at greater risk of breast cancer than non-disabled women (Kelsey *et al.*, 1993) and so attendance is more, rather than less, appropriate.

One audit indicated that people with learning disabilities may not be adequately accessing preventive health care. The findings suggested they were under-served in relation to regular immunisation<sup>8155</sup> with one in five, as compared to four in five of non-disabled people, being immunised. They were also less likely to have urinalysis than the average (less than 1 in 10 compared to more than 4 in 10).

We did not identify any studies that assessed access to specific screening programmes for diseases such as coronary heart disease and so access issues in relation to provision for people with learning disabilities is unclear.

### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- the place of the Special Educational Needs review in providing an overview of health service usage for children with learning disabilities
- mainstream health screening services for people with learning disabilities
- the role of the SEN review in referrals for health care for children with learning disabilities
- the role of residential home medicals in referral for health care for adults with learning disabilities.

Parents reported that there was a lack of co-ordination or overview of the many health service inputs to their children. These parents felt that they themselves had to take responsibility for co-ordinating their child's health care, taking it upon themselves to copy and distribute reports from one health care provider to another. They stated that the only place they felt that they could raise health concerns in a holistic way was during the annual SEN statement review, because this was the only opportunity to address professionals from different health services in one meeting.

Paid carers pointed out that the organisation they worked for provided all its residents with an annual health check but admitted that this was a basic check and unlikely to identify significant health problems. Residents living in the community attended screening clinics at their GP practice, including some well person checks. However, access to such checks for residents based on 'campus' was problematic. The GPs who visited the site did not perform these checks and there was a reluctance to include residents in screening or well person checks at the practice.

### **3.3.4 Availability and appropriateness of Accident and Emergency services**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8193	Freeneay, M., Cook, R., Hale, B. and Duckworth, S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3

Research into the availability and appropriateness of A&E departments for people with learning disabilities was non-existent apart from a single piece of research which addressed accessibility in a range of health service sites.

The study identified addressed the issue of access to hospital A&E services. This study<sup>8193</sup>, also mentioned above in relation to general practice and dental services, found that in addition to the problems of inadequate signage and the inappropriate attitudes and behaviour of staff, on these larger sites inadequate signage also caused considerable problems with 'way finding'. Point of entry difficulties could be significant, with confusion about where to go when reaching the site.

#### **Issues from consultations**

Gaps in the literature were identified in relation to:

- the skills and attitudes of A&E staff in working with children and adults with learning disabilities
- the appropriateness of the physical environment in A&E departments to the needs of children and adults with learning disabilities and challenging behaviour.

Parents suggested, in the same way as paid carers in relation to dentists, that 'it pays to choose your A&Es'. The facilities provided for parents and children were found to vary between hospitals. Therefore, on the basis of experience, parents needing A&E input were likely to approach the hospital whose facilities best suited their child's needs. This included the promptness with which they would be attended to, since waiting rooms were problematic for parents attending with children with severe learning disabilities.

Paid carers found A&E staff wary of the adults they cared for, although this wariness was sometimes used to good effect by carers who suggested that the person might 'kick off' if they were made to wait. The strategy was effective. However, should the visit require admission, carers described lengthy delays caused by inter-departmental disputes over who should take responsibility for care.

## ***From the Cradle to the Grave***

The consultation with family and paid carers identified other issues, similar to those reported in the study on access to A&E services, in relation to staff attitudes. Carers felt that their knowledge and expertise in managing the person with learning disability were often discounted, leading to unnecessary distress for the person and considerable difficulties for A&E nursing staff.

### **3.3.5 Availability and appropriateness of specialist clinics**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
299	Moss, S. and Patel, P. 1993. 'The prevalence of mental illness in people with intellectual disability over 50 years of age, and the diagnostic importance of information from carers'. <i>Irish Journal of Psychology</i> 14: 110–29	Quantitative	Older adult (50+)	All	2
1032	Mansell, S., Sobsey, D. and Calder, P. 1992. 'Sexual abuse treatment for persons with developmental-disabilities', <i>Professional Psychology Research and Practice</i> 23: 404–9	Quantitative	All	All	3
4405	Munden, A.C. and Perry, D.W. 2002. 'Symptoms of depression in people with learning disabilities: Knowledge of various members of the multidisciplinary team involved in the care and assessment of challenging behaviour', <i>Journal of Learning Disabilities</i> 6: 13–22	Quantitative	Older adult (60+)	All	3

## From the Cradle to the Grave

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
4702	Kon, Y. and Bouras, N. 1997. 'Psychiatric follow-up and health services utilisation for people with learning disabilities', <i>British Journal of Developmental Disabilities</i> 43: 20–6	Quantitative	Adult	All	3
4793	Gravestock, S. and Bouras, N. 1995. 'Services for adults with learning disabilities and mental health needs', <i>Psychiatric Bulletin</i> 19: 288–90	Quantitative	Adult	All	3
5317	Sham, S. 1996. 'Reaching Chinese children with learning disabilities in greater Manchester', <i>British Journal of Learning Disabilities</i> 24: 104–9	Qualitative	Adolescent (to 18)	All	3
8120	Department of Health. 1999. <i>Facing the Facts: Services for people with learning disabilities, a policy impact study of social care and health services</i> . London: Department of Health	Report	All	All	3
8193	Freeney, M., Cook, R., Hale, B. and Duckworth, S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3
8273	Smiley, E., Cooper, S.A., Miller, S.M., Robertson, P. and Simpson, N. 2002. 'Specialist health services for people with intellectual disability in Scotland', <i>Journal of Intellectual Disability Research</i> 46: 585–93	Quantitative	NR	NR	3
8503	Carter, B., McArthur, E. and Cunliffe, M. 2002. 'Dealing with uncertainty: parental assessment of pain in their children with profound special needs' <i>Journal of Advanced Nursing</i> 38: 449–57	Qualitative	NR	Profound	3
<u>2636</u>	Cambridge, P. 1996. 'Men with learning disabilities who have sex with men in public places: mapping the needs of services and users in south-east London', <i>Journal of Intellectual Disability Research</i> 40: 241–51	Quantitative	Adult	Mild	4

The evidence base on the availability and appropriateness of specialist clinics was larger than many in this section; however, the less

rigorous studies identified addressed a range of issues. Consequently the access evidence for different specialist clinics is small.

Specialist clinics referred to here are those to which a person may be referred by a general practitioner for further investigation or treatment of a condition or disease and not specifically 'specialist' learning disability services.

### ***Children***

A study of parental responses to pain in their children with severe learning disabilities found an overall reluctance to access hospital services<sup>8503</sup>. Parents stated that this was because it was upsetting for the child and largely unproductive because they felt that their child's handicap was largely seen as responsible for pain and other possible causes were therefore not investigated. As mentioned above in relation to general practice, there are additional communication difficulties for families from ethnic minorities. Where services were accessed by parents of children with learning disabilities who had settled in the UK from Hong Kong, the translation service often proved inadequate, with the translator not always able to understand the content of what was to be communicated<sup>5317</sup>. In such circumstances the potential for misunderstanding and distrust are exacerbated.

### ***Adults***

A survey of local Social Services and health authorities<sup>8120</sup> on systems in place to support access to health services identified problems in accessing and appropriateness of audiology services in a third of authorities, optometry in more than a third of authorities, and sexual health and family planning clinics, screening and immunisation clinics, and chiropody in just under half of authorities. We identified one study that sought to record the availability of specialist learning disability health services in Scotland<sup>8273</sup>. This study suggested considerable variation between trusts in the learning disability services available, which was not accounted for by geographic distances or responsibility for remote rural communities. The authors suggest that the study provides evidence of a 'postcode lottery' in this provision. They were also concerned that apparently some respondents did not know whether these services were available, suggesting poor integration into generic health provision.

One specialist health need reported as lacking provision is in relation to care for victims of sexual abuse. Many studies, not reviewed here, pointed to the prevalence of and service reactions to sexual abuse of and by people with learning disabilities. However, we only identified one Canadian study which addressed access to specialist health care for these people<sup>1032</sup>. This study found problems with the availability of a service and that difficulties increased with the severity of the learning disability of the victim or abuser. They found the services that were available were not well adapted to the needs of the group.

One British study addressed the availability of services to men with learning disabilities who have sex with men<sup>2636</sup>. The study, although rated poor due to a low response rate and the unreliability of the data given its sensitive nature, highlighted that up to three-quarters of these men were possibly having sex that put them at risk of HIV infection. It was the only study we came across that addressed the issue and therefore it has been included to flag up a need for further research. The author suggested that a service is needed to address safer-sex and sexual health education issues with these men.

The literature pointed to substantial unmet need for specialist mental health services<sup>299 4405</sup>. Two studies reviewed here suggested paid carers found the availability of psychiatric services satisfactory; however, this included specialist learning disability, as well as mainstream psychiatric provision<sup>4702 4793</sup>. Learning disability services were rated as more easy to access than the generic specialist mental health services. Current policy directions promoting the use of mainstream services for people with learning disabilities indicate that the findings of these studies may be more worrying than may be at first apparent. If the specialist learning disability provision on which the paid carers taking part in these two studies appeared to be relying was no longer available, access to psychiatric services may become far more problematic.

A number of the papers we reviewed discussed unmet need and problems in identifying and diagnosing mental illness in people with learning disabilities, but none specifically addressed the adequacy of provision and its effect on access.

### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- the provision of mental health services for children and adults with learning disabilities
- the provision and accessibility of pain clinics for children and adults with learning disabilities as outpatients
- information sharing and confidentiality issues for children and adults with learning disabilities using specialist clinics based at two or more different hospitals
- the role of the school nurse in providing triage prior to seeking specialist advice for children with learning disabilities.

During our discussions with carers, the availability of mental health services for people with learning disabilities was reported as in crisis. Anecdotal evidence suggested that children and adults with learning disabilities were either having to wait unacceptably long periods to access psychiatric consultations, even in crisis situations, or they were being inappropriately placed in generic provision. However, consultations took place only in one region of England and this situation may not be generalisable.

## ***From the Cradle to the Grave***

Other specialist provision that was reported as lacking were pain clinics. Parents suggested that greater availability of pain clinics is needed to provide adequate care and as an information resource for GPs. It was reported that the current outpatient waiting time for an appointment at a pain clinic in this particular area was 21 months. This was seen as particularly damaging for children with severe or profound learning disabilities for whom certain traditional methods of pain control may be unsuitable.

Discussions with parents also revealed some difficulties in accessing care due to a lack of co-ordination between different providers. Medical records in hospital were confidential; however, where the child was attending several hospitals for various complaints it was found that some hospitals declined to make records available because of confidentiality issues. This reluctance to share information could result in a child having to undergo several investigations resulting in substantial delays, when in fact the information was already available in another setting.

Parents also described their reliance on special school nurses to provide a form of 'triage' before making decisions to approach 'continuing' health care practitioners. Whether this triage constitutes facilitation or delay in seeking appropriate health care, depending on the circumstances, is open to debate.

### **3.3.6 Availability and appropriateness of acute hospital services**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8193	Freeney, M., Cook, R., Hale, B. and Duckworth, S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3
8228	Sense. 2001. <i>Who Cares? Access to healthcare for deafblind people. A 'Yes to Access' Campaign Report</i> . London: Sense	Report	NR	NR	3

Though we identified some literature on the experience of people with learning disabilities using acute hospital care, there was virtually no information on the availability and appropriateness of these services for people with learning disabilities. The two less rigorous studies identified both addressed the needs of the wider group of people with disabilities that includes those with learning disabilities.

The studies identified addressed the appropriateness of acute hospitals for people with low levels of literacy and/or additional sensory impairments and agreed that facilities were inadequate<sup>8193 8228</sup>. The studies recommend the adaptation of buildings to provide clear, easy to follow signage and a variety of tactile surfaces to assist people with learning disabilities and those with additional sensory impairments with orientation when using hospital facilities. In addition they suggest that aids, such as loop systems, for use by people with learning disabilities and hearing impairments, were also necessary to enable them to use the facility. Finally they proposed that reception staff and porters needed to be made aware of their roles in facilitating use of hospital premises by people with learning disabilities.

#### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- attitudes and skills of 'front of house' staff in working with people with learning disabilities in hospital
- the availability and appropriateness of acute care for people with learning disabilities.

A representative from the Disability Rights Commission reported that the attitude of some 'front of house' staff can sometimes be unhelpful to people with learning disabilities when accessing acute health care. For example, where assumptions were made about the reason one person was attending, they were directed to the wrong part of the

hospital. This was a considerable deterrent to a person already very unsure about using hospital services.

### **3.3.7 Availability and appropriateness of therapy services**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8175	Steele, B. and Sergison, M. 2001. <i>Improving the Quality of Life of Ethnic Minority Children with Learning Disabilities</i> . Huddersfield: Huddersfield NHS Trust	Mixed	Adolescent (to 18)	All	3
<u>7849</u>	Bristol & District Community Health Council. 1998. <i>'Is anybody listening to us? Perceptions of healthcare from PLD and their carers. Bristol: Bristol &amp; District Community Health Council</i>	Qualitative			4

There was almost no evidence on the availability and appropriateness of therapy services for people with learning disabilities. The better-quality study identified, however, only touched on therapy in a superficial way and the poorer study added little to knowledge.

A study that concerned the needs of children with learning disabilities from ethnic minority families touched on the accessibility of therapists. In this study the children were found to have fewer contacts with physiotherapists and occupational therapists than expected<sup>8175</sup> but it did not explore why this was the case. This may be an area requiring further examination to establish whether language and/or cultural factors are inhibiting access to certain therapies for children with learning disabilities from ethnic minority families.

A further study, methodologically poor because of the lack of information on the participants such that we are unable to say whether it addressed children and adults or just adults, nevertheless documented that informal carers reported difficulties in obtaining speech and language therapy for the person they cared for<sup>7849</sup>.

***Issues from consultations***

Gaps in the literature were identified in relation to:

- the adequacy of physiotherapy provision for children and adults with learning disabilities
- the adequacy of speech and language therapy provision for children and adults with learning disabilities
- the extent of private market provision for therapy to children and adults with learning disabilities.

Parents commented that access to physiotherapy and speech and language therapy was very difficult to obtain. There was a view that once a child was diagnosed with learning disability there was a push by health professionals to get them into school, from as young as age 2, so that they might access these services through that route. However, even this provision was seen as less than ideal, because therapy tended to be given in group sessions in which individual needs were badly addressed. Individual therapy was seen as very difficult to access through the NHS and some parents had resorted to paying for therapy privately.

Paid carers from the residential campus reported that their access to therapy was better than the average because the service employed its own therapists. Consequently, waiting times for the commencement of therapy was minimal. Paid carers based in the associated community housing also accessed this private resource. They commented that they understood there were long waiting lists for NHS therapy services.

***3.4 Entry access to health care***

As the UK health care system revolves around primary health care, where access to secondary service is largely through GP referral, the majority of this section deals with literature relating to access to GP services and through these to secondary health care. In this way this section explores the evidence on 'gaining access' to GP services, as well as evidence that through GP services people with learning disabilities 'have access' to continuing health care. It also examines the evidence that people with learning disabilities are 'gaining access' to other 'entry' health services, particularly dental and optometry services.

### 3.4.1 Entry access through general practice

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<b>2804</b>	Beange, H., McElduff, A. and Baker, W. 1995. 'Medical disorders of adults with mental retardation: a population study', <i>American Journal of Mental Retardation</i> 99: 595–604	Quantitative	Adult	All	1
<b>6250</b>	Lennox, N., Diggins, J. and Ugoni, A. 1997. 'The general practice care of people with intellectual disability: Barriers and solutions', <i>Journal of Intellectual Disability Research</i> 41: 380–90	Quantitative	All	All	1
906	Howells, G. 1986. 'Are the medical needs of mentally handicapped adults being met?', <i>Journal of the Royal College of General Practitioners</i> 36: 449–53	Quantitative	Adult	All	2
1984	Dovey, S. and Webb, O.J. 2000. 'General practitioners' perception of their role in care for people with intellectual disability', <i>Journal of Intellectual Disability Research</i> 44: 553–61	Quantitative	All	All	2
2615	Kerr, M., Dunstan, F. and Thapar, A. 1996. 'Attitudes of general practitioners to caring for people with learning disability', <i>British Journal of General Practice</i> 46: 92–4	Quantitative	All	All	2
2649	Thornton, C. 1996. 'A focus group inquiry into the perceptions of primary health care teams and the provision of health care for adults with a learning disability living in the community', <i>Journal of Advanced Nursing</i> 23: 1168–76	Qualitative	Adult	All	2
2718	Whitfield, M., Langan, J. and Russell, O. 1996. 'Assessing general practitioners' care of adult patients with learning disability: case-control study', <i>Quality in Health Care</i> 5: 31–5	Quantitative	Adult	All	2

## From the Cradle to the Grave

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
4510	Lennox, N.G., Diggins, J. and Ugoni, A. 2000. 'Health care for people with an intellectual disability: General practitioners' attitudes, and provision of care', <i>Journal of Intellectual &amp; Developmental Disability</i> 25: 127–33	Quantitative	All	All	2
5357	Thornton, C. 1999. 'Effective health care for people with learning disabilities: a formal carers' perspective', <i>Journal of Psychiatric &amp; Mental Health Nursing</i> 6: 383–90	Qualitative	Adult	All	2
7925	Gill, F.C. 2000. 'Psychological factors in the delivery of primary health care to people with learning disabilities', Thesis, D. Clin. Psych. Birmingham: University of Birmingham	Quantitative	All	All	2
2420	Bond, L., Kerr, M., Dunstan, F. and Thapar, A. 1997. 'Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes', <i>Journal of Intellectual Disability Research</i> 41: 391–400	Quantitative	All	All	3
4405	Munden, A.C. and Perry, D.W. 2002. 'Symptoms of depression in people with learning disabilities: Knowledge of various members of the multidisciplinary team involved in the care and assessment of challenging behaviour', <i>Journal of Learning Disabilities</i> 6: 13–22	Quantitative	Older adult (60+)	All	3
4478	Goldsmith, S., Cooray, S., Johnston, F. and Williams, G. 2000. 'Good practice, general practice: Identifying the health needs of people with learning disabilities', <i>Journal of Clinical Governance</i> 8: 83–8	Quantitative	All	All	3

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
5646	Langan, J., Whitfield, M., Russell, O. 1994. 'Paid and unpaid carers: their role in and satisfaction with primary health care for people with learning disabilities', <i>Health &amp; Social Care in the Community</i> 2: 357-65	Quantitative	Adult	All	3
7856	Singh, P. 1997. <i>Prescription for Change: A Mencap report on the role of GPs and carers in the provision of primary care for people with learning disabilities</i> . London: Mencap	Quantitative	NR	NR	3
8161	Cook, A. and Lennox, N. 2000. 'General practice registrars' care of people with intellectual disabilities', <i>Journal of Intellectual and Developmental Disability</i> 25: 69-77	Quantitative	NR	NR	3
8193	Freeney, M., Cook, R., Hale, B. and Duckworth S. 1999. <i>Working in Partnership to Implement Section 21 of the Disability Discrimination Act 1995 across the National Health Service</i> . London: Department of Health	Mixed	NR	NR	3
8520	Lennox, T.N., Nadkarni, J., Moffat, P. and Robertson, C. 2003. 'Access to services and meeting the needs of people with learning disabilities', <i>Journal of Learning Disabilities</i> 7: 34-50	Quantitative	All	All	3

The evidence base on general practice was larger than on many other areas of interest. Many rigorous studies exist on the attitudes of GPs to providing services to people with learning disabilities but a more limited amount of evidence, which tended to be less rigorous, was identified on their role in referral to other services.

The GP gatekeeper role means that GPs' knowledge, experience, expectations and assumptions have a profound effect on access to continuing health care for their patients. The small number of people with learning disabilities on each GP's register means that opportunities to gain knowledge and experience in the course of everyday practice are extremely limited. For this reason the literature on the care given by GPs has been reviewed in an attempt to assess its effect on accessing other forms of health care.

One study reported a widespread perception among people with learning disabilities that GPs may refuse to take them onto their list because of the additional time they take in consultations<sup>8193</sup> and

although, as mentioned in the section on organisational determinants of access, there is some limited evidence that some GPs may have considered this as an option<sup>2649</sup>, there appears no published evidence of this having happened in practice.

Studies of the unmet health needs of people with learning disabilities suggest that there may be problems assessing health status in general practice. A comprehensive Australian study detected medical problems in 95 per cent of the people examined<sup>2804</sup>. Forty-two per cent of these conditions were previously undetected; almost three-quarters required specialist care but not all had received it; and half of the participants' conditions were inadequately managed.

General practitioners in Australia and New Zealand also have an essential role to play in providing access to specialists. Studies in both these countries examined GP attitudes to health care provision to people with learning disabilities. The Australian studies suggested that that more than 80 per cent of GPs felt responsible for the medical care of adults with learning disabilities<sup>6250 4510</sup> but only 70 per cent felt the same responsibility towards children<sup>6250</sup>. The New Zealand study revealed only 62 per cent of GPs saw themselves as the key providers of health care for people with learning disabilities in their communities<sup>1984</sup>. They tended not to favour a health promotion or screening role, did not see regular hearing or sight testing as within their remit<sup>6250 1984</sup>, nor see it within their role to ensure dental health needs were addressed<sup>4510</sup>.

### ***Children***

Only one study addressed GP care for children. This study highlighted the potential difficulties for GPs in obtaining relevant health information from specialist services that may affect care<sup>4478</sup>. Although based on small numbers, the authors discovered that information was available on the children's health status, but because it was recorded in disparate locations, unnecessary difficulties were created for GPs in assessing and making referrals. This situation is likely to be a consequence of the fragmentation of responsibilities for the health care of children with learning disabilities. The prominent role of the paediatrician in the health care of children with disabilities may result in confusion over responsibilities for day-to-day health care matters and affect ongoing health care co-ordination.

### ***Adults***

The Australian study<sup>2804</sup> suggested that the difficulties GPs experience in providing health care to this group are due to communication difficulties and commented that communication problems, and poor teamworking with other health professionals and providers, were also barriers. More than three-quarters of GPs were uncertain of the baseline health and behaviour of their patients with learning disabilities and many experienced difficulties examining these patients. This finding was confirmed in a study repeating this methodology with GP registrars<sup>8161</sup>. The original study also found that GPs, by their own admission, lacked knowledge of conditions and complaints that affect this population. They also lacked back-up resources, such as specialists or clinics, which they could consult or refer to. Furthermore, time constraints in consultations were a barrier to care provision. GPs also experienced difficulties accessing other health care systems not geared to the needs of people with learning disabilities. They commented that health problems were exacerbated because people with learning disabilities were not seeking help for themselves, or not doing so early enough to allow effective, timely management of their conditions.

UK studies have also highlighted communication issues between GPs and patients with learning disabilities as compromising access to primary health care which, when compounded by time pressures in consultation, present a formidable challenge<sup>906 4510 7856</sup>. As in Australia and New Zealand, there has been general agreement among GPs that health care for people with learning disabilities is their responsibility<sup>2420 2615 7925</sup> but there is nevertheless a reluctance to organise and deliver health checks, including eyesight and hearing tests<sup>2420 2615</sup>, or make other adaptations to their practice to meet their needs<sup>7925</sup>.

One study noted that more than four in five GPs felt that the health needs of people with learning disabilities are less well met than the rest of the population<sup>7856</sup>. In this study GPs expressed a perception that people with learning disabilities made fewer visits to their surgeries, which they attributed to difficulties with communication, bad experiences in the past and the reluctance of carers to attend with the person they care for. However, studies have also been undertaken that compare the extent of consultations, types of health problems detected and preventive assessments between people with and without learning disabilities. These studies have suggested that consultation patterns are similar, though health problems differ and preventive assessments are less likely to be performed for the people with learning disabilities<sup>2718 5646</sup>. Given the additional health needs experienced, however, a similar consultation pattern to the general public suggests that GP services are under-accessed by this group. Lack of information in medical records on breast and cervical

screening, as well as sight and hearing testing has been taken to show that such services are under-accessed<sup>4478</sup>.

It has been suggested that GPs have missed opportunities for preventive health care screening and medicine review in the course of consultations<sup>5646</sup>. It may be understandable because, given the above evidence, consultations are likely to be challenging even in relation to the presenting condition. However, these missed opportunities were also not picked up by carers<sup>5646</sup>. A study on unmet need found that 41 per cent of people with learning disabilities reporting eyesight problems had not seen an optician, while 27 per cent of those with epilepsy had not seen their GP; 72 per cent with foot problems had not seen a chiropodist and more than 50 per cent with continence problems had not seen a continence advisor, although they were seen by a CNLD who liaised with a continence advisor<sup>8520</sup>. The same study reported that none of the participants with diabetes was regularly seeing their GP, but 91 per cent with mental health needs were seeing a psychiatrist. It has been suggested that difficulties in identifying ill health may also in part be due to diagnostic overshadowing<sup>2804</sup> where the symptom is taken to be part of the learning disability rather than indicating an additional illness. This may be particularly apparent in identifying symptoms of mental illness, particularly depression in adults, including older adults with learning disabilities. Identifying these symptoms has been found difficult for a range of health professionals<sup>4405</sup>.

As noted above in relation to population screening exercises, GPs may withdraw women from their list of patients eligible for cervical screening programmes if they consider them unnecessary. One study of screening referrals for women with learning disabilities found that 37 per cent of women had been withdrawn at the request of the GP<sup>1984</sup>. Once removed from the list the woman will not be called unless her GP specifically requests her name to be added.

Within the general practice setting the difficulties outlined above have tended to give the family or paid carer, who almost always accompanies the person to their appointment, a great deal of influence in the health interview. Some studies have highlighted this and noted instances where carers have had significant influence on health care and treatment decisions<sup>5357</sup>.

***Issues from consultations***

Gaps in the literature were identified in relation to:

- the responsiveness of entry-access health professions to the health concerns of people with learning disabilities, and parents and paid carers
- the success of GPs in making timely referrals to continuing health care services for children and adults with learning disabilities
- the influence of family and paid carers on GP care
- communication skills and tools to facilitate effective health interview and appropriate referral.

Parents reported that in their dealings with health professionals, including GPs, they have needed to be assertive to gain access to health care they considered their child needed. Some health professionals were seen as dismissive of concerns and parents reported a need to be persistent and to battle against 'gatekeepers' of health care to gain referrals. However, they also pointed to the vulnerability of children with learning disabilities whose parents were not articulate and assertive in their dealings with health professionals.

Discussions with parents suggested that they were happy with the role of their GP in co-ordinating multiple referrals up to the point when their child's diagnosis was confirmed. However, once they began receiving regular hospital care GPs tended to abdicate responsibility for health care management and continually refer back to hospital. Where mothers discussed their health concerns about their child with the GP they felt that GPs could be dismissive, tending to see symptoms as part of the learning disability, for example: 'This is a frail, special needs child. You've got to expect to have problems'. The small group of parents consulted for this study recounted two instances where the health concerns they had raised with GPs were not recognised as symptoms of quite serious complaints that had later required hospitalisation. Parents expressed specific concern over GP knowledge regarding epilepsy and over obtaining referral to specialist neurology services.

For those living in residential care, paid carers described two different types of GP provision, as noted in the section on organisational determinants of care. Carers based at the residential campus felt that, due to the long-standing involvement of the two GPs providing the on-site service, they had developed specialist expertise in learning disabilities. Carers acknowledged that the GPs provided ongoing monitoring of chronic conditions but felt they were reluctant to refer on to specialist services. Once again, problems with accessing specialist neurology services, even through these GPs, were mentioned.

People with learning disabilities living in the community reported that they used local GP services. All these individuals reported being happy with their doctor who they felt did talk to them directly about their

health to a greater or lesser extent. However, they also stated that they went to their appointment with a carer and relied on the carer to absorb the information the doctor was giving them. For this reason they were happy to have their carer with them. Although it is reassuring to hear that these adults appreciated assistance from their carers in this situation, it is perhaps also an indication that skills in communicating health information to people with learning disabilities need to be addressed.

The influence of parental wishes on access to health care was also noted in our consultation with paid carers. They had found on occasions that referral to health services could be blocked by parents who had bad experiences with health care in the past. Similarly, other parents had not allowed any medical treatment for their daughter without their personal approval because her disability was caused by vaccine damage. This led to delays in seeking treatment and in inappropriate use of medication.

### **3.4.2 Entry access through dentists and opticians**

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8383	Speechley, M. 2002. <i>Adults with profound and multiple learning disabilities: perceived and real obstacles to accessing vision testing services</i> , dissertation. Manchester: University of Manchester	Quantitative	Adult	Profound	3

No evidence on barriers to gaining access to dental health services, other than that noted in the section on organisation of health care, was identified. Only one study was identified that addressed the barriers to 'gaining access' to optician services. This thesis identified similar barriers for people with profound learning disabilities in accessing 'vision-testing services', to those described in studies of access to general practice, including physical access issues, communication problems, and the attitudes to and knowledge of people with learning disabilities among health professionals<sup>8383</sup>.

In the course of routine dental and eye examinations there may be need to refer the patient for specialist input at dental or eye hospitals. This is particularly the case for dentistry, where referral for orthodontic treatment is relatively common. We found no studies that looked at referral of people with learning disabilities to orthodontic or prosthodontic clinics. We also identified no studies on referral to specialist optical health services.

For adults, dental problems associated with tooth development, requiring specialist referral, are less likely to be an issue because these tend to be addressed throughout childhood. However, for older

adults the need for prosthodontic treatment through tooth decay may re-surface as an issue. Nevertheless it was surprising that access to specialist dental services for children did not appear to have been explored.

***Issues from consultations***

Gaps in the literature were identified in relation to:

- referrals to specialist dental services by primary care dentists
- access to mainstream optometry for children and adults with learning disabilities
- the attitudes and skills of primary care dentists to working with children and adults with learning disabilities.

Parents again reported that access to dental services was routed through the special school to a 'Special Needs' dentist (part of the Community Dental Service) because of their son or daughter's challenging behaviour. Experience of this service was not entirely satisfactory: a dentist in one case was reported to have taken eleven years to persuade a boy to open his mouth. In the meantime, the need for intervention had escalated. For a girl with autism and severe epilepsy, satisfactory provision had only been achieved by capitalising on opportunities to perform examinations when she was 'having a good day' at the residential facility she had been referred to because of behavioural difficulties.

Other parental experiences with 'mainstream' dentists had suggested that bridgework and other restorative treatments may be seen as 'cosmetic' for this group because of a perception that the child has no opinion on the state of his or her appearance, so the need to maximise attractiveness, as well as functionality, is superfluous. However, the parents consulted emphasised that physical attractiveness was important for their children, because it affected the extent to which people they came in contact with were prepared to interact with them.

Carers of adults who lived in community housing and who did not have challenging behaviour reported that they were able to access general dental services but that there were individual practitioners who had greater expertise than others in providing a service to people with learning disabilities. When these practitioners were identified, carers made sure that other residents also registered with that dentist. Some young people with learning disabilities consulted reported that they used local dentists. They visited these practitioners with a carer and were happy to do so.

Parents also stated that they were unable to use high-street opticians because of physical access difficulties and their son's and daughter's challenging behaviour and again accessed a specialist service through school. Young people with learning disabilities however appeared to be

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accessing optometry services through hospitals that they had first attended as children. It is unclear how far this practice extends.

### 3.4.3 Entry access through clinics, community service providers or A&E

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<b>2804</b>	Beange, H., McElduff, A. and Baker, W. 1995. 'Medical disorders of adults with mental retardation: a population study', <i>American Journal of Mental Retardation</i> 99(6): 595-604	Quantitative	Adult	All	1
<b>6250</b>	Lennox, N., Diggins, J. and Ugoni, A. 1997. 'The general practice care of people with intellectual disability: Barriers and solutions', <i>Journal of Intellectual Disability Research</i> 41: 380-90	Quantitative	All	All	1
<b>8377</b>	Clarke, C. 2002. <i>Living with a Learning Disability in Northumberland</i> . Newcastle: Northumbria University	Qualitative	NR	Moderate	1
8240	Slevin, E. 1995. 'Student nurses' attitudes towards people with learning disabilities', <i>British Journal of Nursing</i> 4: 761-66	Quantitative	All	All	3
<u>8363</u>	Firth, M. 1982. 'How good is professional support following a diagnosis of mental handicap?', <i>Health Visitor</i> 55: 215-20	Qualitative	Pre-school	NR	4

The evidence base on referral to secondary care via routes other than the GP was extremely small and of variable quality.

### ***Children***

An exploration of the experience of mothers of recently diagnosed pre-school children with learning disabilities<sup>8363</sup>, which was poor in terms of academic rigour, was the only study identified that examined the role of generic community nurses in obtaining access to health care. The study suggested that the mothers often felt that their worries were trivial and that consultation time pressures meant that it was inappropriate to bring up some issues with the GP. Health visitors were the only sustained professional contact in the year following diagnosis for many of the mothers interviewed and were often instrumental in obtaining health services such as speech therapy or therapeutic equipment. The mothers found their health visitors more accessible than their GP in 'sudden need' and more able to visit the family home.

### ***Adults/older adults***

A comprehensive Australian study<sup>2804</sup> suggested that people with learning disabilities as a whole had increased prevalence of factors associated with poor health outcomes and an increased number of chronic diseases that were frequently not recognised. Difficulties in accessing specialist health care through routes other than GP care, such as through other specialist health professionals or A&E, may be affected by availability of services appropriate to the needs of people with learning disabilities, and lack of knowledge of the conditions or complaints suffered by this group<sup>6250</sup>. Where emergency admission to hospital was required, one British study found that decisions to admit appeared more related to the person's additional needs, such as mental health status, age or anti-social behaviour, than their therapeutic need to receive treatment for the identified condition<sup>8377</sup>.

The literature reports that student nurses who experienced contact with people with learning disabilities during training showed more positive attitudes towards them as a group<sup>8240</sup>. This study suggests that some of the difficulties in accessing clinic or accident and emergency services may be improved by training for nurses and other care staff that involves personal contact with the group.

### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- the role of the school nurse in facilitating access to continuing health care
- the role of Community Learning Disability Teams in referrals to continuing health care.

Parents emphasised the important role played by primary care professionals during the early stages of diagnosis of learning disabilities and associated conditions. However, by far the most

extensively used route to specialist care for children after diagnosis, apart from their GP, was said to be through the special school. As noted above, this suggests a large role for school nurses in securing access to continuing health care although we found no literature exploring this role.

Paid carers confirmed that, in relation to adults, the residential campus providing care facilitated access to ongoing specialist health care, particularly therapies, by buying in the services independently. Routes to such care for adults who do not have this kind of independent provision, apart from via the GP, are likely to include referral through CLDTs. However, we found no literature examining the role of these teams in accessing specialist care.

### ***3.5 Continuing access to health care***

Many services to which people with learning disabilities may be referred will involve ongoing contact over the longer term. In regard to conditions such as epilepsy, only periodic health appointments will be required to review experience of epileptic seizures in the recent past and review medication prescribed. In relation to other treatments much more frequent contact is necessary to derive and maintain benefit. This is particularly the case with physiotherapy, where withdrawal of the service for even a few weeks may result in loss of flexibility or strength achieved in muscle tone. Timely 'continuing' access to these services is crucial to maintenance of optimal health status. This section therefore considers the evidence on whether people with learning disabilities 'gain access' to continuing health services.

#### **3.5.1 Continuing access to specialist outpatients hospital clinics**

<b><i>ID</i></b>	<b><i>Authors</i></b>	<b><i>Study type</i></b>	<b><i>Age group</i></b>	<b><i>Disability level</i></b>	<b><i>Rating</i></b>
82	McGrath, C.W., Bhaumik, S., Thorp, C.F., Watson, J.M. and Taub, N.A. 2002. 'Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire, UK', <i>Journal of Intellectual Disability Research</i> 46: 299–309	Quantitative	Adult	All	2

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<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
8095	Beecham, J., Chadwick, O., Fidan, D. and Bernard, S. 2002. 'Children with severe learning disabilities: needs, services and costs', <i>Children and Society</i> 16: 168–81	Quantitative	Primary school	Severe	2
8288	Foundation for People with Learning Disabilities. 2002. <i>Count Us In: Report of the Committee of inquiry into meeting the mental health needs of young people with learning disabilities</i> . London: Foundation for People with Learning Disabilities	Report	Adolescent (to 18)	NR	2
4642	Roy, A., Martin, D.M. and Wells, M.B. 1997. 'Health gain through screening – Mental health: Developing primary health care services for people with an intellectual disability', <i>J Intellect Develop Dis</i> 22: 227–39	Quantitative	Adult	NR	3
8228	Sense. 2001. <i>Who Cares? Access to healthcare for deafblind people. A 'Yes to Access' Campaign Report</i> . London: Sense	Report	NR	NR	3
8240	Slevin, E. 1995. 'Student nurses' attitudes towards people with learning disabilities', <i>British Journal of Nursing</i> 4: 761–66	Quantitative	All	All	3
8252	Pearson, M., Flynn, M., Maughan, J. and Russell, P. [no date] <i>Positive Health in Transition: A guide to effective and reflective transition planning for young people with learning disabilities</i> . Manchester: National Development Team	Qualitative	All	NR	3
8501	Optimum Health Services NHS Trust. 1998–1999. <i>Young Adults Transition Project: Draft Final Reports 1–3</i> . London: Optimum Health Services NHS Trust	Qualitative	NR	Severe	3

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<u>8505</u>	Heslop P., Mallett, R., Simons, K. and Ward, L. 2002. <i>Bridging the Divide at Transition: What happens for young people with learning difficulties and their families?</i> Kidderminster: BILD	Quantitative	Adolescent/young adult	NR	4

### **Children**

Two studies address access to 'continuing' services and both of these relate to mental health services. One study identified physical health problems and illness as risk factors for developing mental health problems<sup>8288</sup>. Given the increased prevalence of health problems among children with learning disabilities, this implies an increased risk of developing mental illness. A separate study of service provision to children with learning disabilities found a weak association between severity of behaviour problems and contact with a clinical psychologist or psychiatrist<sup>8095</sup>. Even so, none of the children identified in the study as having one or two severe problems had accessed this service. That is, it appeared that only those with the most extreme behaviour gained access to services. The authors suggest that this result indicates under-provision of mental health services to children with learning disabilities.

### **Adults/older adults**

Even when people with learning disabilities are referred to a specialist service, continuing access may not be assured. A study of access to specialist services following a comprehensive health check found that continuing access to psychiatric services was not as successful as access to physical health services<sup>4642</sup>. The authors suggest that the symptoms seen as chronic by carers might not be seen as severe enough to warrant intervention by professionals. They found disputes about where people with learning disabilities should be referred and reluctance by professionals with high workloads to respond to referrals from screening.

One study on the service needs of people with learning disabilities from South Asian communities found that these people had fewer contacts with psychiatrists than people from white communities<sup>82</sup>, despite similar needs. This study did not, however, investigate the reasons for lower attendance rates. Literature reviewed above has highlighted a dearth of mental health services for people with learning disabilities in general; the findings of this study therefore suggest a double barrier to accessing mental health services.

The success of services in providing access to ongoing care is to some extent dependent on the attitudes of those who provide the service. That is, negative attitudes or demanding situations, in terms perhaps of the extent to which the service user is left to negotiate their own way to the service setting, may determine whether patients continue to access clinics. These circumstances, particularly in terms of physical access and the need for equipment to enhance communication, are especially challenging for people with additional sensory impairments who tend to feel that their needs as outpatients are not fully understood<sup>8228</sup>. However, a study, mentioned above, showed that specific training involving a period of contact with people with learning disabilities effected a positive attitude change among student nurses<sup>8240</sup>.

A subject of considerable debate in the literature was the transition from child to adult services, particularly in relation to 'continuing' health services such as those addressed here. Access to 'continuing' health services after attaining adulthood has been found to be a difficult experience for many young people with learning disabilities<sup>8252 8501 8505</sup>. Success in continuing to access these services may be dependent upon supply relative to need and demand<sup>8252</sup>; on availability of funding; and on agreement over respective responsibilities between child and adult services<sup>8501</sup>. One study described particular difficulties in relation to assessment of need and attitudes and skill of staff<sup>8252</sup>. Transitions from children's to adult hospital services tended to be experienced as the most problematic, particularly for those with more severe disabilities, including learning disabilities, who access several clinics<sup>8501</sup>. Changes in epilepsy services were reported to cause considerable distress to young adults with learning disabilities and continued access to mental health services was also problematic<sup>8252</sup>.

### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- the attitude and skills of hospital nurses in working with children and adults with learning disabilities
- the roles and responsibilities of mainstream psychiatry and specialist learning disability services in the provision of mental health care to children and adults with learning disabilities
- the appropriateness of providing ongoing health care reviews without physically examining children or adults with learning disabilities
- communication skills and tools for effective service provision to children and adults accessing continuing health care.

Parents discussed at some length their anxieties about accessing hospital care which they thought ill-adapted to the needs of children with severe or profound learning disabilities. Particular problems were experienced if their child needed to remain in hospital overnight. They

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felt that nursing staff did not appreciate the amount of supervision these children required, to the extent that carers dared not even leave the children 'unattended' while they used the bathroom.

There were particular concerns over the availability of mental health services which were perceived to be crisis-driven. Parents reported prevarication between psychiatry and learning disability services in relation to responsibility to provide for people with learning disabilities.

Other comments from the consultation groups suggested some issues with ongoing reviews. Parents had experienced reviews where the child was not examined, which were instead conducted by talking to parents, and medication doses were then altered by e-mail. It is unclear why this situation occurred, or for whose benefit this type of review was developed. Taking children with severe or profound learning disabilities to hospital outpatient appointments is likely to be challenging for everyone involved and parents are likely to be the greatest source of information available for ongoing assessment. However, it is reasonable to assume that some information may be gained by actual physical contact with the child that may not be gleaned from parents.

Community learning disability service staff identified a 'reverse stigma effect' whereby mainstream hospital staff were reluctant to label a person as learning disabled because it was deemed unkind. However, failing to identify such people deprived them of an opportunity to receive support to access hospital services. Similarly, the mother of a woman with learning disabilities who took part in our consultation exercise pointed out that health staff sometimes made assumptions about someone's ability to understand health-related information based on their appearance. She reported that her daughter felt too embarrassed to admit that she didn't understand and so potentially important information was lost. This connects with a study reported above which found that carers over-estimated the ability of individuals to understand and retain information<sup>211</sup> and points to a need to develop appropriate communication tools or skills for those responsible for service delivery.

### **3.5.2 Continuing access to therapists**

Despite the need to 'gain access' to therapies in a continuing way in order to maintain their effectiveness, and despite the difficulties encountered in gaining initial access to this type of service, we found no research literature addressing issues in ongoing access to therapy.

#### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- the appropriateness of providing group *versus* individual physiotherapy to children with learning disabilities
- the difficulties in providing uninterrupted physiotherapy and speech and language therapy to children and adults with learning disabilities.

Parents and paid carers emphasised the problems of accessing physiotherapy and speech and language therapy in particular. For children, parents suggested that they were unable to obtain individual therapy. The consequence of this practice for the children was said to be that some children with minimal need for therapy obtained more input than required while children with greater needs did not have all their needs addressed.

Paid carers commented that although they had access to a privately purchased physiotherapy service on the residential campus, they found difficulties in maintaining therapy in periods when the therapist was unavailable. Staff commented on the rapid decline in flexibility during interruptions to provision experienced by people with learning disabilities who needed regular therapy.

Both groups stressed the importance of regular input to maintain health gains for people in need of this type of therapy.

### **3.6 Innovations designed to improve access to health care**

The problems experienced by people with learning disabilities in accessing mainstream health care have been recognised for some time among specialist learning disability health providers. Consequently some local providers have sought to initiate changes to improve the situation. Unfortunately few of these have carried out research into the effectiveness of the intervention. It is possible that where an initiative has been implemented and appears to work well, the need to evaluate may appear superfluous (Rossi, 1987). A number of studies were identified; however, these may significantly under-represent the work going on among, in particular, community learning disability health services to promote access to health care. This section

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therefore explores the evidence on innovations intended to improve access to health care for people with learning disabilities.

### 3.6.1 Innovation

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
1607	Webb, O.J. and Rogers, L. 1999. 'Health screening for people with intellectual disability: the New Zealand experience', <i>Journal of Intellectual Disability Research</i> 43: 497–503	Quantitative	All?	All	2
6248	Jones, R. and Kerr, M. 1997. 'A randomized control trial of an opportunistic health screening tool in primary care for people with intellectual disability', <i>Journal of Intellectual Disability Research</i> 41: 409–15	Quantitative	Adult	All	2
8359	Kerr, A.M., McCulloch, D., Oliver, K., McLean, B., Coleman, E., Law, T. <i>et al.</i> 2003. 'Medical needs of people with intellectual disability require regular reassessment, and the provision of client- and carer-held reports', <i>Journal of Intellectual Disability Research</i> 47: 134–45	Quantitative	NR	All	2
8470	Cumella, S. and Martin, D. 2002. <i>Improving Primary Health care for People with a Learning Disability. A report commissioned by East Riding Health Authority.</i> Birmingham: University of Birmingham	Mixed	NR	All	2
8521	Martin, G. 2003. 'Annual health reviews for patients with severe learning disabilities', <i>Journal of Learning Disabilities</i> 7: 9–21	Quantitative	Adult	Severe	2
1608	Barr, O., Gilgunn, J., Kane, T. and Moore, G. 1999. 'Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland', <i>Journal of Advanced Nursing</i> 29: 1482–91	Quantitative	Adult	All	3

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<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
1898	Lennox, N.G., Green, M., Diggins, J. and Ugoni, A. 2001. 'Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study', <i>Journal of Intellectual Disability Research</i> 45:226–32	Quantitative	Adult	All	3
2086	Bollard, M. 1999. 'Improving primary health care for people with learning disabilities', <i>British Journal of Nursing</i> 8: 1216–21	Quantitative	Adult	All	3
4642	Roy, A., Martin, D.M. and Wells, M.B. 1997. 'Health gain through screening - Mental health: Developing primary health care services for people with an intellectual disability', <i>J Intellect Develop Dis</i> 22: 227–39	Quantitative	Adult	NR	3
5342	Paxton, D. and Taylor, S. 1998. 'Access to primary health care for adults with a learning disability', <i>Health Bulletin</i> 56: 686–93	Quantitative	Adult	All	3
5748	Dodd, K. 1999. "'Feeling poorly": Report of a pilot study aimed to increase the ability of people with learning disabilities to understand and communicate about physical illness', <i>British Journal of Learning Disabilities</i> 27: 10–15	Quantitative	Adult	Moderate	3
5859	Hunt, C., Wakefield, S. and Hunt, G. 2001. 'Community nurse learning disabilities: A case study of the use of an evidence-based screening tool to identify and meet the health needs of people with learning disabilities', <i>Journal of Learning Disabilities</i> 5: 9–18	Quantitative	Adult	All	3
6271	Wells, M., Turner, S., Martin, D.M. and Roy, A. 1997. 'Health gain through screening - coronary heart disease and stroke: Developing primary health care services for people with intellectual disability', <i>J Intellect Develop Dis</i> 22: 251–63	Quantitative	Adult	NR	3
8217	Halliwell Surgery. 2002. <i>Learning Disability</i> . Available at: [ <a href="http://www.halliwellssurgery.com">http://www.halliwellssurgery.com</a> ] [ <a href="http://www.gmclardy.doctors.org.uk/ldl">http://www.gmclardy.doctors.org.uk/ldl</a> ]	Report	Adult	NR	3

<b>ID</b>	<b>Authors</b>	<b>Study type</b>	<b>Age group</b>	<b>Disability level</b>	<b>Rating</b>
<u>2114</u>	Allan, E. 1999. 'Learning disability: promoting health equality in the community', <i>Nursing Standard</i> 13(44): 32-7	Quantitative	Adult	All	4
<u>7886</u>	Nadarajah, J. and Gingell, K. 1991. 'A community based walk-in clinic for mentally handicapped adults - is there a need?', <i>Psychiatric Bulletin</i> 15: 544-5	Quantitative	Adult	All	4

The evidence base for innovations was larger than many other issues; however, most of these were less rigorous or poor methodologically. Twelve of the sixteen papers identified addressed implementation of some form of health check or screen, two further papers described walk-in/pop-in clinics, one paper described a GP consultation intervention and the last involved an intervention aimed primarily at people with learning disabilities themselves.

***Improving access to health care by increasing the health knowledge and communication skills of people with learning disabilities***

One study described and evaluated an intervention directed at people with learning disabilities themselves. They implemented a health education programme for ten people with learning disabilities using a communication tool developed to help them identify their health needs, and communicate about health with carers and health care professionals<sup>5748</sup>. The authors reported substantial improvement in knowledge of what to do when feeling ill; why and how to visit the GP; the role of the receptionist; the need to provide symptom information; and what happens in a consultation. The majority of these people were reported to have retained this information at a six-month follow-up interview. The researchers found increases in knowledge of the body and bodily processes for many, although there was some reduction in this knowledge at follow-up. Those found to have the highest levels of knowledge or skill retention were those who had occasion to use the knowledge and the specially developed communication aid in the intervening period. As the authors acknowledge, they were only able to obtain limited information on the usefulness of the intervention, because in addition to the small sample size, few of the people involved had episodes of ill health in the intervening period and so had no opportunity to use their knowledge or skills. In addition they were unable to follow up participants from one particular residential facility.

Although this was a small-scale study, with some major methodological limitations, it suggests that health education and communication aids may be helpful for people with learning disabilities who are able to use them, in communicating about health. A large part of the literature reviewed above suggested that a fundamental barrier to accessing health care was recognition of need. Programmes such as the one described here may be one way to enable individuals with less severe learning disabilities to self-advocate. Use of the communication aid, which was also provided to the participants' GPs, may also provide a means of overcoming some of the communication difficulties they experience in the consultation. The fact that this is reported to be a pilot study suggests that the authors may be in the process of conducting a much larger study on the development and effectiveness of this programme.

***Improving access to health care for people with learning disabilities through GP consultation***

In the course of the review, many papers (for example, <sup>6250</sup>) referred to the difficulties GPs experience in providing a service to this group, including lack of knowledge of the health problems that affect people with learning disabilities, communication difficulties, examination difficulties and time constraints, and suggestions on strategies to improve this situation. However, no literature was identified that evaluated the effectiveness of implementing any of these suggestions, or reporting that these were becoming part of GP practice – for example, booking double-length appointments, attending education or training in health conditions affecting people with learning disabilities, or ensuring continuity of care by fostering ongoing relationships between a specific general practitioner, the person with learning disabilities and their carer. Only one study examined a proposed change to GP consultation practice. The study aimed to improve preventive health care opportunities, and by implication timely and appropriate access to secondary care, by developing a 'note prompt', to be kept with the patient's notes in the document wallet<sup>6248</sup>. The prompt recorded basic details of support services available, as well as consultation considerations that research has shown most important in the health care of people with learning disabilities. At follow-up it appeared that the card prompt had no significant effect on consultation patterns or health promotion when compared to people with learning disabilities whose notes did not contain the prompt. However, an audit of notes provided evidence of more preventive health input to people with learning disabilities who were 'new' to the service. They concluded that this was the main opportunity for health promotion and that GPs are unlikely to provide other routine screening on an opportunistic basis.

Two studies examined the effect of health checks on the knowledge and skills of general practice staff. An Australian pilot study aimed to improve access through general practice by implementing GP-conducted health checks. They found that this was a useful way of increasing or clarifying GP awareness of the needs of their patients with learning disabilities<sup>1898</sup>. The checks also provided an opportunity to review aspects of care which were not the GPs' main responsibility, but which they were able to provide access to. Similarly a health check service implemented in the UK described several benefits gained by practice staff<sup>2086</sup>. Practice nurses' understanding and awareness of this client group increased as well as their knowledge of specific services available to them. GPs were also reported to benefit from becoming aware of patients with learning disabilities registered with the practice. Almost half of the GPs felt that they had become more aware of the health needs of the group, and more than three-quarters reported being more aware of specialist learning disability services.

***Improving access to health care through comprehensive health checks***

As noted above, twelve studies reported on the use of health checks or screens to improve access to health care for people with learning disabilities. Many of these interventions reported identification of high levels of unmet health needs<sup>1607 1608 5342 5859 4642 8470</sup>. For example, a study in New Zealand found 73 per cent of those screened required health actions; most of these were health promotion activities, and some were reviews of existing treatments<sup>1607</sup>. A study in the UK identified health need in all but one of 38 participants in a health check programme implemented in two general practices<sup>8470</sup>. These studies acknowledged the effectiveness of health checks in highlighting unmet need and their importance in obtaining adequate recognition and funding for development of services<sup>1608</sup>. However, messages from these studies varied as described below.

Two studies on implementing health checks examined the role of the learning disability nurse as a 'health facilitator'<sup>5859 8470</sup>. The role was slightly different in each study with one community nurse in learning disability (CNLD) taking on an 'organisational' role centred around identifying the target population and consulting people with learning disabilities and their carers about the problems they had in accessing health services<sup>8470</sup>, while the other focused on a 'personal' service to the person with learning disability to facilitate access, including pre-visit preparation for health appointments<sup>5859</sup>.

The 'organisational' health facilitator role was judged to be effective in terms of identifying undiagnosed morbidity, raising awareness and generating local solutions<sup>8470</sup>. The 'personal' health facilitation, provided in the second, addressed communication barriers through the CNLD attending mainstream health appointments with the person and their carer and was as described successful in providing concise, accurate, and relevant information from the health check. It was suggested that the CNLD also provided support to the GP supplying information on specific conditions related to learning disabilities. They helped to prepare people with learning disabilities for appointments or procedures they were scheduled to receive. However, the stated value and effectiveness of the role in each case appeared to be based on the judgement of the authors alone, with no independent verification from the patients, carers or other health professionals.

One study used the concept of health checks as a means to improve GP care of patients with learning disabilities<sup>1898</sup>, while three more assessed the impact of health checks on referral to other services<sup>1608 4642 5342</sup>. In one of the latter group of studies, 87 per cent of people with learning disabilities or their carers reported that they had followed up the health concerns raised during the review and had subsequently experienced health improvements<sup>1608</sup>. A separate study considered the success of psychiatric referrals made based on the use of a mental health screening tool<sup>4642</sup>. Approximately one-third of people screened were identified as potentially suffering mental health problems but less than half were in contact with specialist mental health services. However, none of those referred as a result of screening had managed to access mental health services approximately one year later. Difficulties with referrals were also evident in the third study which made a range of referrals to the GP or other services such as optometry or audiology. Although accessing services did not appear problematic and people with learning disabilities and carers generally expressed satisfaction with the services available, some recommended referrals were not followed up and so health services were not accessed. The authors stress the importance of the carer role in facilitating access to services but highlighted difficulties convincing people with learning disabilities and their carers of the importance of some checks, particularly eyesight testing<sup>5342</sup>.

A recent study also addressed the issue of vision and hearing testing<sup>8359</sup>. Comprehensive sight and hearing screening found major discrepancies between needs as perceived by carers and those established by expert assessments. For example, nursing carers reported 'perfect vision, requiring no intervention' for 49 per cent of their clients but only four of those assessed (less than 1 per cent) were judged to have completely normal sight. For hearing, 74 per cent were perceived to have normal hearing compared to only 11 per cent assessed as normal through specialist testing.

Other health check studies have addressed the issue of health gain<sup>6271</sup>  
<sup>8217 8521</sup>. However, only one attempted to evaluate health gain. This study focused on people with learning disabilities attending annual checks<sup>8521</sup> but found difficulties assessing whether health conditions had improved or deteriorated because changes in paid carers meant that they were unfamiliar with the person's former health status. This suggested that adequate record keeping is vital to determine whether gains have been made. They found that initial referral rates to psychiatrists, Community Learning Disability Teams (CLDTs) and other colleagues appeared to tail off after two years, suggesting a 'front-loading' effect of long-standing problems that had accumulated, unrecognised, for many years.

Another study suggested that health gains could be made by screening for risk factors for chronic heart disease for which, the authors suggest, this group would appear to have a greater prevalence<sup>6271</sup>. A further study reported that access to preventive health care had improved for patients with learning disabilities registered with one practice over a two-year period<sup>8217</sup>. Follow-up health checks revealed a similar level of unmet need identified as in initial checks. However, no specific information was provided on individual gains as a result of health checks in either of these studies.

What is important from the standpoint of this literature review is the effect that health checks have had on access to services. The evidence seems to point to success in identifying need, provision of preventive interventions, and referrals for continuing care. However, the studies appear to suggest that where the organisational determinant of access is the person's carer, access may not always be achieved. Carer influence on access to health care for people with learning disabilities is such that if they are not convinced of the need for health assessments or treatment, access to 'entry'-level health services will not be sought. In addition, shortages in provision, such as that suggested in specialist mental health care, may result in low priority being accorded to people with learning disabilities referred through screening.

### ***Improving access through 'walk-in' clinics***

Two studies, neither of which were satisfactory methodologically, described initiatives to set up 'walk-in' or 'pop-in' clinics at Adult Training Centres in order to improve access to services<sup>2114 7886</sup>. These were the only studies to report on this type of initiative.

One study aimed to improve access to mental health care by setting up a clinic in an Adult Training Centre<sup>7886</sup>. Although this was reported to be a 'walk-in' clinic, appointments were made at the request of carers or other health professionals. The only self-referral experienced was from someone wanting dental care. Feedback from carers about the clinic found that 89 per cent (n=19) said the clinic was useful and made referral easier.

The second study set up clinics run by community learning disability nurses in two Adult Training Centres<sup>2114</sup>. They reported on 30 consultations (self-referred) undertaken at the first centre (unfortunately 12 of these were with carers) and 44 at the second clinic. The author stated that each service user had at least one health need identified by the service, many of which did not require GP referral and were dealt with directly. However, no feedback on the success of the initiative was sought from other sources.

These types of clinics appear to provide an accessible service for some people with learning disabilities using day centres. It is unclear how accessible walk-in clinics, based on self-referral, are to people with severe or profound learning disabilities. However this type of provision is contrary to stated policy objectives that people with learning disabilities should use mainstream services rather than specialist provision, and this is perhaps the greatest argument against pursuing this type of provision.

### ***Issues from consultations***

Gaps in the literature were identified in relation to:

- provision of health checks for children with learning disabilities
- the effectiveness of a hand-held health record in facilitating access to 'entry' and 'continuing' health services for children and adults with learning disabilities.

None of the innovations reviewed here addresses innovative schemes aimed specifically at children, and only one practice-based health check service invited children to attend as well as adults<sup>8470</sup>. The reasons why children do not 'have access' to such services are not clear. It is possible that assumptions are made about the extensiveness of health checks or other surveillance available to children through the paediatrician. Discussions with parents suggested that some kind of health check may be welcome and provide the holistic view that some felt was lacking and being filled, inappropriately, by the Special Educational Need review for some children.

Both parents and paid carers reported that it would help the person they cared for to 'gain access' to services if they had some kind of hand-held health record, or health passport, which would carry details of their medical history, their communication style, any challenging behaviours, and guidance on how behaviours may be managed, or avoided. Paid carers felt that this sort of record could get around some of the problems of using agency/bank staff to accompany people to appointments, and could be helpful for mainstream health professionals caring for them during admission to secondary care. Parents felt that such records would be useful for ensuring that details of their child's needs, and important aspects of their medical history, are available to health professionals. Parents commented that at times they overlooked reporting some aspects of their child's condition to

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health professionals because they had become so familiar with them they tended to assume everyone else was aware of them.

## Section 4 Summary and conclusions

We identified a considerable amount of literature on improving the health status of people with learning disabilities, of which 'access to health care' is a fundamental component. However, much of the literature that initially appeared highly relevant to the review was often actually only marginally or implicitly related to access, focusing instead on practice issues or guidelines to care. In the review we remained focused on our remit and only included studies that were substantially addressing issues related to our model of 'access' to health care.

Overall, 839 papers were screened using the full text and 183 were found relevant to the access model. However, 101 of these were either reviews, reports with no original data, or low-quality studies addressing areas of the model where we had already identified a number of more robust studies. Eighty-two studies were fully assessed and are included in the review. The studies included 15 qualitative, 62 quantitative and 5 mixed method studies.

The evaluation stage identified five highly rigorous studies (rated 1), 22 rigorous studies (rated 2), 46 less rigorous studies (rated 3) and 9 methodologically poor studies (rated 4). The later were retained because they addressed issues not covered in more rigorous studies.

Although 82 studies may appear to be a substantial evidence base, the broad definition of 'access' used meant that once they were divided into areas of the model, gaps in the literature appeared. Table 4 below shows the distribution and quality of the evidence throughout the model.

**Table 4 Distribution and quality of evidence identified by the review**

<b>Area</b>	<b>Highly Rigorous</b>	<b>Rigorous</b>	<b>Less Rigorous</b>	<b>Poor</b>	<b>Total*</b>
<b><i>Wider determinants of health</i></b>					
Health promotion	–	–	1	–	1
<b><i>Identification of need</i></b>					
People with learning disabilities	–	1	2	1	4
Parents/carers	1	7	13	2	23
Others	–	–	–	1	1
<b><i>Organisational determinants</i></b>					
GP services	–	4	5	–	9
Dental services	1	–	4	–	5
Optometry services	–	–	–	–	0
Screening/surveillance	1	1	6	–	8
A&E	–	–	1	–	1
Specialist outpatient clinics	–	1	8	1	10
Acute services	–	–	2	–	2
Therapy	–	–	1	4	5
<b><i>Entry access</i></b>					
GP services	2	7	9	–	18
Dental services	–	–	–	–	0
Optometry services	–	–	1	–	1
Community health/ services/A&E	2	–	1	1	4
<b><i>Continuing access</i></b>					
Specialist outpatient clinics	–	3	5	1	9
Inpatient services	–	–	–	–	0
Therapy	–	–	–	–	0
<b><i>Innovation</i></b>					
Communication aid	–	–	1	–	1
GP practice	–	1	–	–	1
GP practice-based health check	–	4	8	–	12
Walk-in clinic	–	–	–	2	2

\* Totals add to more than 82 because studies addressed more than one area of the model

The table demonstrates that most evidence was found on identification of need by carers and GP services, while in other areas the evidence was scant.

## ***4.1 The model***

The levels of the model worked well in helping to clarify user and practitioner or provider roles in access along the 'access continuum' described by Gulliford *et al.* (2001). Specifically, access is described as some point along a continuum between initial contact with, and utilisation of services. However, it became apparent that 'organisational determinants' ran through all aspects of access to health care for people with learning disabilities and was not separate from the formal demand for care. It was also noted that access issues in entry and continuing health care interacted with one another such that, to some extent, access to continuing health care was related to, and dependent on access to effective 'entry' health care services. Here 'entry' health services are defined as first contact services to which a person must refer themselves (primary care), while 'continuing' health services (secondary care) include those with which people are likely to have a long-term relationship on a more or less regular basis and need a referral from another health practitioner. Access to hospital investigations, such as blood testing, by primary care physicians is considered part of primary care because in these circumstances GPs are using hospital facilities as a tool in their own diagnosis and care of individuals. No evidence was identified by this review of access to these investigative health services by people with learning disabilities.

People with learning disabilities are particularly dependent on others to facilitate access to health care. This dependency begins outside the health care system but continues throughout all efforts to access entry and continuing health care. For people with learning disabilities 'having access' requires not only the existence of a suitable service appropriate to their current health need, but carer and professional assistance so that they may 'gain access' to it.

The review has shown therefore that the model requires some revision to accommodate, conceptually, the access needs of people with learning disabilities. Figure 2 represents this development.

## ***4.2 Evidence from the review***

Below we summarise the literature identified by the review. The evidence may appear disjointed in some areas; however, this is a reflection of the literature that we were able to identify. This section is followed by a discussion of the gaps in the literature identified in consultation with people with learning disabilities, parents and paid carers, and representatives of national organisations of and for people with learning disabilities.

***Wider determinants***

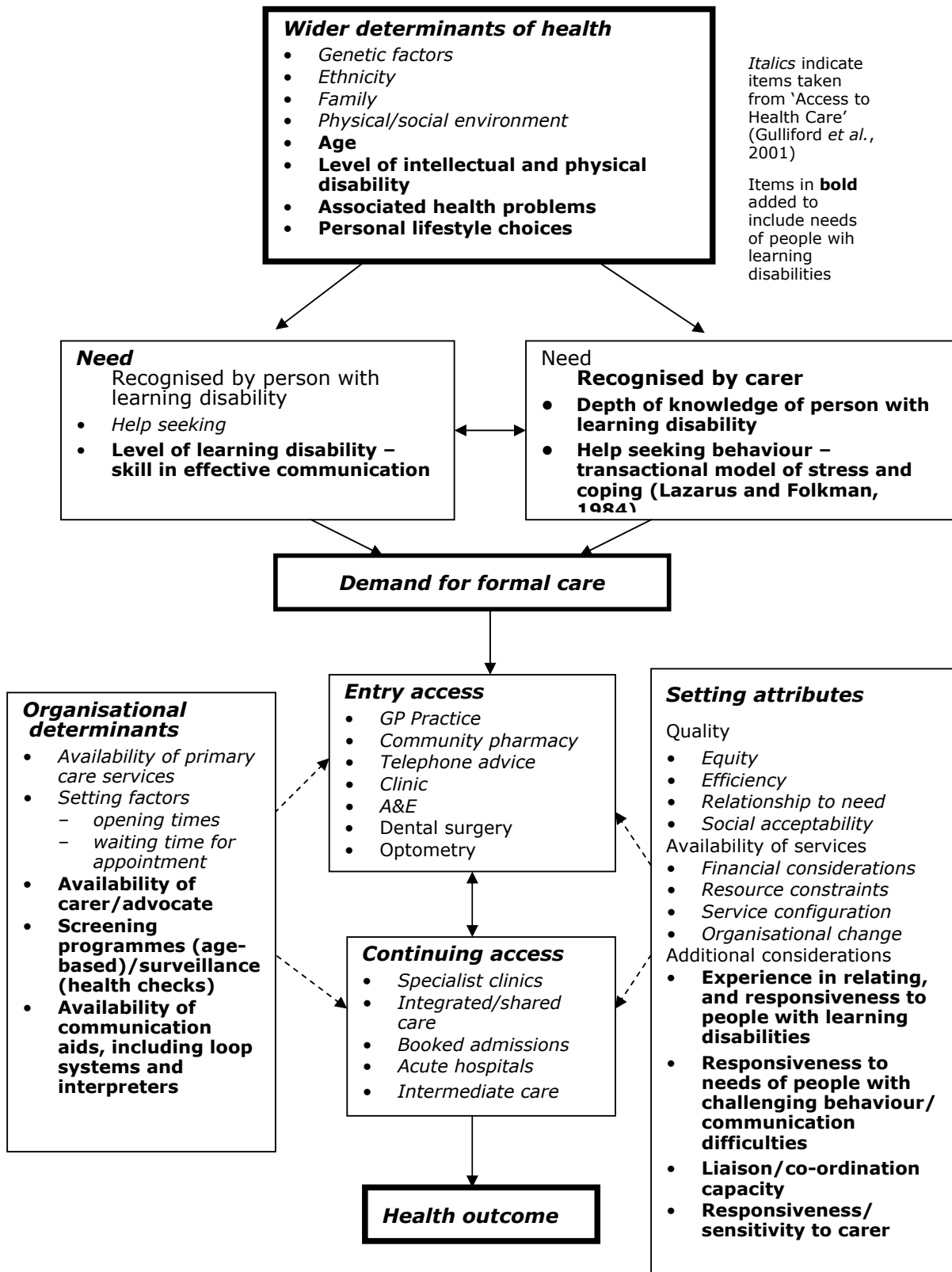
There was only one, less rigorous, study identified in this area. This study on health promotion suggested that attempts to promote health lifestyle choices were not well co-ordinated. Service providers with policies on the matter, mostly trusts and hospitals for people with learning disabilities, were more likely to have implemented initiatives than those who did not have policies.

***Identifying health need***

A much larger literature was identified on identifying unmet health need, again mainly less rigorous in terms of quality but with several rigorous studies and including one highly rigorous study. The majority of these studies addressed identification of need by informal or formal carers. Overall the evidence suggested that people with learning disabilities had difficulty in identifying and/or communicating health need. Children were found to have a muted pain response and to be less likely to seek help from adults than normally developing children, while paid carers had difficulties in identifying non-verbal signals from adults with severe or profound disabilities, not able to communicate verbally. Women with mild learning disabilities, in a methodologically poor study, reported that they did not like to approach maternity services because of apprehensions about what would happen; about not being able to answer questions; and because they perceived health service personnel held negative attitudes about their pregnancy and ability to cope. This evidence suggests that even where people with learning disabilities have recognised a need that they wish to communicate to a carer, or approach services about, depending on the severity of their disability they may be unable or unwilling to do so.

The little evidence identified in relation to children suggested that some parents perceived their child had learned to live with pain, which is an understandable assessment if they experience only muted pain responses from their child. However, it suggests that more investigation is needed on whether it is the pain or the communication of pain that is muted, and should it be the former, does this imply that the underlying cause warrants no further investigation? This information is needed so that parents may take appropriate action in response to signals.

**Figure 2 Revised model of access to health care for people with learning disabilities**



Other research involving parents addressed the needs of children with learning disabilities living in an immigrant Chinese community. This research suggested that culture and language difficulties formed a barrier to accessing health services for these parents because they might not accept or understand the diagnosis of learning disability. Other research reported that educational attainment could affect willingness to approach services, with higher-attaining parents being most likely to seek help. However, there was no exploration of why this may be the case.

A considerable amount of evidence suggested that paid and family carers had difficulties identifying health need in adults with learning disabilities despite any health monitoring they may undertake. For adults with severe learning disabilities the value of long-term relationships was confirmed in helping to identify changes in physical state or behaviour that deviate from the norm and may indicate ill health, particularly for people with severe learning disabilities. However, identification of poor hearing and eyesight has been shown to be more difficult to determine. Even where deficits are suspected, this may not prompt action to seek health care if it is perceived as unnecessary because of the severity of the learning disability suffered by the individual (overshadowing). Other studies also suggested that where health promotion issues are identified by carers, they do not always bring them to the attention of their general practitioner. There was some evidence also that carers had problems identifying mental health problems in the person they cared for. However, it was noted in a study of older adults that carers may be aware of symptoms but fail to recognise these as indicating ill health.

There was virtually no evidence on the role of other professionals in identifying health need in people with learning disabilities. A single, methodologically poor, US study looked at the role of school nurses in identifying need. It suggested that these nurses were well placed to facilitate health care for children with learning disabilities.

### ***Organisational determinants***

A wide range of studies were identified and again the majority were less rigorous; however, there were a few rigorous and two highly rigorous studies. More studies addressed GPs than other types of care. Studies addressing specialist clinics focused on a range of services. Two studies identified additional problems for children from South Asian families in accessing health care due to language difficulties. This evidence, together with that from the study on Chinese families noted above, suggested difficulties with the translation services. Problems were experienced with inconsistency in the availability of a translator or link worker, or with the competence of the translator to translate the medical information to the family.

A comprehensive study on the physical accessibility of a range of health services found difficulties with signage and unhelpful attitudes

of reception staff as presenting barriers to access. This study of physical access to NHS premises also suggested that people with learning disabilities experienced problems using hospital premises because of poor signage and had difficulties finding their way around the site. The perceptions of people with learning disabilities that GPs may refuse to register them, also reported in this study, was not verified by other evidence reviewed here. However, a survey of general practices in a separate study reported that refusing registration had been considered by some GPs as a means of avoiding the considerable demands that these patients were expected to place on the practice. Physical difficulties in accessing services were also reported for people with additional sensory impairments. Equipment to aid communication for people with sensory impairments was not found to be widely available in primary or secondary care settings.

A small amount of literature addressing organisational determinants of access to dental care suggested that children with learning disabilities were less likely to access dental services than non-disabled children. It was reported that some mothers were reluctant to put them through what they perceived would be distressing experiences. Similarly it has been suggested that adults with learning disabilities living in informal family settings in the community have higher levels of tooth decay than people living in formal residential care. Those in family settings were reported as less likely to see a dentist regularly, or to have no dentist and only seek care when experiencing pain. Some confusion and difficulty was reported around losing registration with NHS dentists if the service was not accessed over a fifteen-month period. Once a registration has been lost it is not always possible to re-register because the practice list may be full.

Literature on health screening noted difficulties for women with learning disabilities in accessing cervical cancer screening and mammography. The evidence suggested that not all women eligible are invited to screening and that inappropriate means may be used in informing those who are invited. Assumptions on the part of general practitioners and carers about the appropriateness of performing cervical screening for more severely disabled women have been reported in some studies to result in failure to invite for screening, or in non-attendance. Similarly, studies found that assumptions about the appropriateness of mammography screening led to the names of some women with learning disabilities being withdrawn from lists of those eligible for screening.

An audit found evidence that people with learning disabilities were less likely to have received preventive health care than members of the general population, suggesting that they were failing to access regular immunisation and were less likely to receive urinalysis than the average for other practice patients.

Other than issues of physical access noted above, virtually no literature was identified on access to hospital services. A single study

reported that parents of children with severe learning disabilities may be reluctant to access hospital services because it was upsetting for the child and may be unproductive because health concerns were dismissed as being part of the child's disability.

A survey of local provision in place in 21 local authority areas to support access to health services found problems with accessing, and the appropriateness of, audiology services, optometry services, sexual health and family planning clinics, screening and immunisation clinics and chiropody services. A separate study in Scotland also recorded variability in the availability of specialist learning disability services.

Many UK studies reported on issues relating to sexual abuse of, and by, people with learning disabilities, but none addressed access to health care for people in relation to this abuse. However, one Canadian study reported problems with the availability of suitable services for people with learning disabilities who suffer sexual abuse. A British study, which was poor methodologically, suggested a need for a service for men with learning disabilities who have sex with men and who therefore are putting themselves at risk of HIV infection.

There was scant evidence on the organisational determinants of access to mental health services. Evidence reviewed suggested considerable unmet need for specialist mental health services. However, other research suggested that formal carers were relying on specialist learning disabilities services to supplement poor levels of specialist mental health provision.

In relation to the organisational determinants of access to therapies, the only references we found suggested that children from ethnic minority families had fewer contacts than would be expected in relation to their needs. However, these studies did not elaborate on the causes. A second, methodologically poor, study reported informal carers had difficulties in obtaining speech and language therapy.

***Entry access***

More of the studies identified here were of rigorous or better quality than in other areas of the model, though an equal number were less rigorous. This evidence on access issues in 'entry' access services centred on general practice. These issues related to access to GP services, as well as their role in referral on to secondary specialist health care. Evidence noted above reported perceptions of people with learning disabilities that GPs may refuse to take them onto their list because of the extra demands providing for their needs would make on the practice. The limited evidence identified suggested this had been a consideration for some GPs surveyed, when taking people with learning disabilities on to their list, but these GPs did not report that this had happened in practice.

Literature on the attitudes of GPs towards providing health care to people with learning disabilities suggests general agreement on responsibility for the day-to-day health care of these patients. However, many also acknowledge that they lack knowledge of learning disabilities and the associated conditions. There was also reluctance among many GPs to become involved in organising health screening or checking programmes. They did not feel they had a role in facilitating access to sight or hearing testing, nor in ensuring dental needs were met.

One study suggested that the information needs of GPs may not be well met, not because information from specialist colleagues is not available, but because the information was not kept in a form that could be easily referred to when needed.

Communication difficulties, time constraints and examination difficulties have all been found to affect the GP's ability to provide an effective primary care service with clear implications for referrals to secondary care where these are needed. Limited evidence suggested that GPs felt they lacked back-up resources to work with this group and were restricted by a secondary health service not geared to meet the needs of people with learning disabilities. Evidence on the frequency of GP contacts with people with learning disabilities varied. Some studies, mainly Australian, suggested higher rates of contact than the general public; other, UK, studies suggested similar rates compared with the non-disabled population; and yet others suggested lower rates in comparison to other vulnerable groups. Overall, the evidence suggests that GP services may be under-accessed, especially in view of the acknowledged greater health needs experienced by people with learning disabilities.

A more limited evidence base suggested that GPs were missing opportunities for preventive health screening and medication review in the course of consultations but that carers were also not making requests for these services as they identified a need for them. Difficulties were also noted in relation to identifying symptoms of

mental illness in older adults with learning disabilities, again with implications for referral to secondary care.

A small amount of evidence, described above, suggested that people with learning disabilities may not be accessing dental health care to the same extent as the non-disabled population. However we found no evidence addressing access issues arising within primary dental practice itself. Evidence was entirely lacking in relation to primary (first-contact) optometry services. Given the unmet need established in many of the studies reviewed here, research on access to these services and through these services to specialist dental or optometry care, would appear warranted.

Evidence on access to, and through, other community-based or entry health services was very limited. One study, poor methodologically, reported that access to secondary health services for young children with learning disabilities was often facilitated by the health visitor. Other, highly rigorous, research suggested that the same difficulties with communication and lack of knowledge and back-up resources which have been described as affecting GP provision, were likely to affect other services, such as accident and emergency provision. However, a less rigorous study of trainee nurses demonstrated positive changes in attitudes following specific training.

### ***Continuing access***

Evidence on access to continuing health services was patchy and small, tending to be less rigorous but with a few better studies. Several studies suggested a lack of, or inappropriate, provision of mental health services to children, adults and older adults with learning disabilities. People with learning disabilities from South Asian communities were also shown to have fewer contacts with psychiatrists than people from white communities, despite similar levels of need.

A small amount of evidence suggested that negative or unhelpful attitudes towards people with learning disabilities could affect continuing access to health services. It was reported that those with additional sensory impairments have greater difficulty than other people with learning disabilities in accessing this type of health care because their needs may not be fully understood.

Transition to adult services for children with learning disabilities has also been shown to be problematic. Where successful, transition has been related to adequate supply relative to need and demand; availability of funding; and agreement over the respective responsibilities between child and adult services. More often, the attitudes and skills of staff, as well assessment of need, were shown to be problematic. These difficulties are exacerbated for children with complex health needs who access several specialist clinics. There was a suggestion that continuing access to epilepsy and mental health

services throughout the child/adult service transition caused particular difficulties.

Access to therapy services appeared particularly problematic. Evidence described earlier suggested that there was a shortage of services such as physiotherapy and speech and language therapy. However, we found no evidence on continuing access to therapy services for people with learning disabilities and so were unable to explore the issues of ongoing access to these services.

We also identified no literature on access to inpatient care. Literature was identified that explored issues of diagnostic overshadowing which could potentially impact on access to inpatient care. However, the focus of these studies tended to address the existence of the phenomenon, and the difficulties of making accurate diagnoses, but not its implication for access.

### ***Innovations***

A small and varied literature was identified on initiatives implemented to try to improve access to health care for people with learning disabilities, most of which was evaluated as less rigorous, with a small number of rigorous studies, but two that were methodologically poor.

A single study developed a communication aid and training package for people with learning disabilities about health and using health care. The numbers of people involved were small, although they reported some success at improving personal knowledge of health-related issues. However, the communication aid was not widely used during the trial period and so it was not possible to properly evaluate its usefulness.

Another study trialled the use of a 'note prompt' card that listed support services available, and considerations suggested by research as important in the health care of people with learning disabilities. However, the prompt did not appear to have an effect on consultation patterns or health promotion for the experimental group compared to controls over the trial period. An audit conducted as part of the same study suggested, however, that more preventive health actions were experienced by people with learning disabilities who were new to the practice, and that this was where health promotion was taking place. A small amount of further evidence was reviewed of the effect of conducting health checks on GP knowledge and skills in relation to learning disabilities. This, exclusively Australian, literature suggested that health checks conducted by GPs increased or clarified their awareness of the needs of their patients with learning disabilities and provided an opportunity to review aspects of care that were not the GPs' main area of responsibility. Similarly, a single UK study suggested that implementing a health check service increased practice nurses' understanding and awareness of this client group, as well as their knowledge of specialist services available to them. GPs also

benefited by becoming aware of their patients with learning disabilities.

The majority of the evidence evaluated described implementation of health checks. High levels of unmet need were uncovered in all these studies, but the message from the studies varied. Two described the health facilitation provided by a Community Nurses in Learning Disability (CNLDs), while three more assessed the impact of health checks on referrals to other services. The evidence on the impact of health checks on access to health services was therefore small. It suggested that carers also had a degree of influence on whether referrals were followed through, and that referrals to psychiatry appeared unsuccessful, at least in the twelve months following the check. A single study attempted to measure health gain as a result of conducting health checks, but it was not possible to determine the effect of the check because of the 'turnover' in paid carers looking after the person which meant their current carer was not aware of their earlier health status. The researchers did, however, note that initial referral rates to psychiatrists, Community Learning Disability Teams and other colleagues appeared to tail off after two years, suggesting a 'front-loading' effect of long-standing problems that had accumulated, unrecognised, for many years.

Two further studies, both poor methodologically, described the implementation of 'walk-in' clinics at Adult Training Centres. One of these clinics focused entirely on mental health needs and required referral from family or paid carers. It was reported to facilitate access to mental health services. The second was a general clinic run by a nurse and appeared to rely on self-referral. It was reported to be well used and to identify and remedy need resulting in time savings for GPs. However, the effectiveness of these clinics could not be established from these reports.

### **4.3 Gaps in the literature**

Gaps in the literature are discussed in the subsections that follow. The issues are organised into those occurring outside health care settings and those occurring within them. Issues outside health care settings relate directly to people with learning disabilities themselves; to parents and paid carers; to residential homes; and to other community service professionals. Issues inside health care settings relate to 'entry' health care services; to 'continuing' health care services; and to overarching issues that affect all service levels.

#### **4.3.1 Factors affecting access that lie outside health care settings**

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

The literature identified on the difficulties experienced by people with learning disabilities in recognising and communicating signs and symptoms of ill health was very limited and did not fully explore the implications for accessing health care. Communication presents challenges at every level and while the literature on health services represented this barrier to care well, there was no exploration of the effect of failures in communication at a pre-service level, that is, the difficulties people with learning disabilities may have in communicating their distress to a parent or paid carer. There was also no exploration of the effect that challenging behaviour has on identifying health need or accessing health care.

##### ***Parents and paid carers***

The literature identified a pivotal role for parents and carers in facilitating transport to, and communication during, health consultations. However, it does not presently explore the full extent to which parents and carers are capable of identifying health need in the person they care for. The literature, and comments from parents and carers, suggest that identifying health need becomes increasingly problematic for those with the most severe levels of learning disabilities. Current literature also does not address help seeking by parents and paid carers in relation to health need. Questions therefore remain unanswered concerning the point at which a parent or paid carer considers that a sign or symptom is of significance and needs monitoring, requires action to alleviate distress, or requires health advice from a professional. Issues related to the care of men with learning disabilities by women were also not addressed. This issue is likely to affect more able men with learning disabilities, who may be too embarrassed to discuss sensitive issues with female staff.

A major theme that recurred throughout the consideration of access to 'entry' and 'continuing' health care services was that of parent and paid carer influences on both entry access to health care and continuing access. However, the impact of carers on access within the health care system does not appear to be well researched.

Communication difficulties appear to force health professionals to rely heavily on the carer that accompanies the person with learning disabilities to provide information and in many cases give consent to treatment or referral. In making referrals, it is necessary to obtain the consent of the person who is to be referred to specialist services. For adults, it is currently not legal for anyone other than the person concerned to give consent for treatment. However, evidence from studies on sterilization for non-medical purposes has highlighted the practice of parents, in particular, providing consent to treatment. Our consultations suggested that parents and paid carers may also influence which primary health service practitioners the person registers with; the treatments or referrals accessed as a result of using health services; and even medical reviews, where the person is not seen at review but information from parents is used as a basis for medication adjustment, in absentia. Therefore there is a particular need for research into the influence of parents and paid carers on access to continuing health care.

### ***Residential homes***

The literature review and our consultations highlighted a number of gaps in relation to people with learning disabilities living in formal residential care. An issue not addressed in the literature was the effect of staff shortages on access to health care. Service responses, as noted during our consultations, to this situation involved taking other residents along to the appointment, or using agency or bank staff to accompany the person to their appointment. Both responses, although ensuring the person 'had access' to the service, affected the extent to which they were able to 'gain access' to the service, because the quality of the communication within the consultation was affected.

Access to health care for people living in segregated settings also appears under-researched. If mainstream services are to be providers to the *whole* population (Department of Health, 2000), then some investigation is needed into how to ensure that people living in segregated settings may be included. Within residential campuses there are also issues to be addressed as to the hierarchical nature of staff relationships and its effect on access to health care. 'Chains of command' could potentially introduce delays into appropriately accessing health care. We also found no evidence on the role of 'home medicals', or routine health checks, on access to health care. There appears to be potential for such medicals to identify need and facilitate referral.

Other professional groups working with people with learning disabilities are potentially in a position to identify health need or to refer to health care: in particular, the role of the school nurse in identification of health need; provision of 'triage', that is a medical opinion on the need for more specialised medical advice, before approaches to health care by parents; and referral for health care needs to be explored. It was apparent from consultations with parents that, at least for children with severe learning disabilities, school nurses were making referrals to specialist dental and optometry services, as well as for physiotherapy and speech and language therapy. Within education, one may consider that teachers may also have a role in identifying health need. However, we identified no literature examining their role in this regard.

It also became apparent from consultations that the Special Educational Needs Review was being used, at least by these parents, as a means to obtain co-ordination of the health care provided from a range of services and also to flag up unmet need. How far it is within the remit of these reviews to perform this role is unclear and we found no evidence describing the SEN review as a route through which children with learning disabilities access health care.

For adults, we found no evidence that other professional workers with whom they may have daily contact, such as day centre staff, were actively involved in identifying health need or seeking referral directly, or through parents or paid residential carers, to health care. There also appears to be a need for clarification of the role of these and other satellite care workers, such as those involved in daily transportation or respite care, in relation to accessing health care.

### **4.3.2 Factors affecting access that lie within health care settings**

#### ***'Entry' health services***

Evidence on primary care services suggested that GPs accepted that they had a role in the day-to-day health management of people with learning disabilities, yet it was also apparent that there were difficulties in making timely, appropriate referrals to specialist health services. The evidence on the reasons for difficulties in this regard appears well rehearsed, as noted above. However we identified no literature which demonstrated that any of the suggested solutions to overcoming barriers, such as double-length appointments, have been implemented in a systematic way. It is unclear how many GP practices have made changes to accommodate the needs of people with learning disabilities on the basis of this evidence, or the effectiveness of doing so. Literature on the reluctance of general practitioners to initiate routine health checks or other practice changes, in the face of so many other demands on their services, suggest that those GP

practices that have changed may be the exception rather than the rule.

The evidence on access to dentists by people with learning disabilities was very limited. It appeared that some more able people with learning disabilities may be accessing general dental services but that people with severe learning disabilities or challenging behaviour may be accessing specialist dental services. The relationship between level of disability and the type of care accessed was not explicit, however, but was implied by the few studies reviewed and comments from parents of children with severe and profound learning disabilities. We were also surprised that we did not find any literature on referral to specialist dental services such as orthodontics or prosthodontics. There would appear to be a gap here in the information about whether and how children and adults with learning disabilities are accessing these specialist services.

There was no evidence as to whether people with learning disabilities access optometry services with the same frequency as non-disabled people. Studies on identification of unmet health need found high numbers of people with visual problems. However, we could find only one thesis on access to optometry for adults with learning disabilities. The optometrists taking part reported similar barriers to access as have been reported by other 'entry health services', namely physical access, administrative difficulties, and communication problems.

Comments from parents about the difficulties of using 'high-street' opticians, and on the role of the school nurse in accessing optometry, suggest that the latter is the route to care currently used by children with severe learning disabilities. How this equates with policy directives on using mainstream services (with support) is unclear and requires investigation. Comments from young adults with learning disabilities and paid carers suggested that some more able adults were able to use local provision, but others were still using the hospitals that they first attended as children. Again, level of disability may be the root cause of these differences, with people with more severe learning disabilities using specialised hospital services while more able people access mainstream optometry. Two people with learning disabilities who took part in consultations did not have severe learning disabilities but nevertheless used hospital services for their eye care. However, they both appeared to suffer particular sight problems and one was registered blind.

The evidence on health checks and health screening was mixed. Health surveillance or health checks have been designated 'innovations' intended to improve access and so will be considered separately. Evidence on access to population screening initiatives however focused mainly on screening for cervical cancer. The evidence here suggested that not all women with learning disabilities were able to access cervical cancer screening, partly because they were not invited; partly because they were invited using inaccessible means of

communication, and partly because third parties made decisions about the suitability of the service for the woman concerned. We found no initiative that aimed to overcome these barriers. Although there was less evidence, the situation for mammography appeared similar. We found no evidence on whether people with learning disabilities were gaining access to other screening initiatives such as those covering people at risk of chronic heart disease.

The evidence on access to accident and emergency services was very limited and of poor quality. Parents and paid carers reflected on their experiences of using A&E, suggesting that some departments provided a more accessible service than others. Accessing A&E was particularly problematic for parents with a child with learning disability and challenging behaviour, where the physical environment of the department had an effect on whether that department would be used. This suggests a need for research on the features of A&E services that facilitate access for children and adults with learning disabilities, particularly those with challenging behaviour.

### ***'Continuing' health services***

Little evidence was identified concerning access to continuing health services. However, this evidence, and the comments from people consulted, centred in the main on the lack of appropriate provision. Mental health services, in particular, were described as poor and some confusion or prevarication over the role of mental health *vis-à-vis* learning disability health services was in evidence. Consequently learning disability services may be approached inappropriately in relation to mental health problems. In addition to shortage of mental health services, these approaches may reflect confusion among some carers and professionals as to the distinction between learning disability and mental ill health. The accessibility of mainstream psychiatric provision for children and adults with learning disabilities needs to be assessed, as well as the relationship and relative roles of psychiatry and learning disability provision.

Other shortages of research evidence identified in consultations, and in a very small literature, related to pain clinics and physiotherapy in particular, but also speech and language therapy. In relation to physiotherapy, the extent to which children with learning disabilities were able to access to individual care was unclear. For both children and adults, problems with access appeared to result in some parents or other relatives seeking private provision. Ongoing access to physiotherapy was also an issue. That is, having initially accessed the service, it is unclear whether people with learning disabilities gain access to uninterrupted appropriate provision.

The literature reviewed on unmet health needs also suggested that audiological services were under-accessed, particularly by older adults with learning disabilities. We found no evidence addressing access to audiology for people with learning disabilities.

## **4.4 Overarching issues and conclusions**

The following issues affect all health service provision and need to be taken into consideration in policy and research.

### ***Lifespan***

As described in the Introduction (Section 1), most of the evidence we identified on access to health care related to adults, or in some cases did not specify the age range. A limited literature was found in relation to children that addressed a few of the areas of concern investigated in this review. However, the literature relating to access to health care for older adults with learning disabilities was almost non-existent. Some literature was found relating to mental health needs, but other literature merely noted the relationship between increasing levels of need and increasing age and issues of access were not explicitly addressed. The reasons for this are unclear, but perhaps rooted in an assumption that the health care needs of older adults are no different from those of younger adults.

### ***Ethnicity***

The evidence in relation to access to health care for people from ethnic minority communities was small and consisted of sections within wider studies on access to a range of services. This literature confirmed additional difficulties for people from ethnic minorities due to language difficulties; inconsistent access to interpreters; or use of interpreters who failed to understand the content of what they had to relate. There was passing mention of reduced contact with psychiatry and therapists compared to the white population, but no exploration of why this should be the case. Issues of access to health services for people with learning disabilities from ethnic minority communities therefore need much more thorough investigation.

### ***Help seeking***

It is evident that 'help seeking' is a vital precursor to 'accessing health services'. As indicated above, individuals vary in their responses to stressful symptoms; their subsequent actions are influenced by a range of factors including their own personal characteristics, such as personality and coping style, as well as their current physical, mental and material resources in relation to the seeking healthcare.

For people with learning disabilities who rely on carers for support, these factors are complicated by the interaction between the two parties. Difficulties in identifying and communicating need on the part of people with learning disabilities may lead to inappropriate conclusions on the part of carers as to the urgency of identified need. The consequences are that the coping response, which may ultimately entail help seeking, is based on flawed information about the nature of the stressful symptoms, or illness.

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Overcoming these difficulties requires proactive approaches from health services, as outlined above, including targeted education programmes to increase the likelihood of people with learning disabilities and carers appropriately identifying need; and programmes of health assessment which facilitate identification of need and can support help-seeking from appropriate mainstream health services.

### ***Level of learning disability***

As described earlier in this report, because severity of learning disability is likely to affect levels of health need and other attributes such as mobility and challenging behaviour, we felt it appropriate to try to gather evidence on access issues in relation to people with different levels of learning disability. Unfortunately this has not proved possible. Most studies addressed themselves to 'people with learning disabilities' in general. Some studies attempted to ensure they had drawn a sample that was representative of the range of levels of learning disabilities. However this strategy could serve to mask issues specific to particular groups. The need for differentiation was reflected to some extent in our consultation groups, where more able adults with learning disabilities said they were able to use mainstream services but parents reported having to use specialist services for their children with severe learning disabilities. It is entirely plausible that what is timely and appropriate provision to a person with a mild level of learning disability may not suit someone with a severe disability at all.

The relationship between level of disability and the type and appropriateness of health care that is accessed needs to be addressed in policy and research. People with learning disabilities may be supported through a range of measures to access mainstream services. However, a minority of individuals have learning disabilities or additional needs that are so severe that use of 'ordinary' entry (first-contact) health service facilities is not feasible. For these patients, provision of 'entry' health services by mainstream health professionals, such as GPs, who are contracted to provide 'enhanced services', may provide the opportunities that these patients require to use mainstream services.

### ***Stigma***

People who lack competence in daily living tend to be less valued, or less highly regarded, than those who are able to demonstrate their self-sufficiency in terms of personal care and economic independence, with greater value being placed on those who demonstrate unusually higher competencies in their chosen field of endeavour.

Learning disability has a profound effect on competence, and many people with learning disabilities are unable to demonstrate competence in even the most basic personal care. Consequently they have not been valued highly as individuals. The stigma of

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incompetence has forced many more-able people with learning disabilities to deny their need for support, and prompted some charged with caring for them in mainstream services to avoid labelling their disability because it is deemed unkind. People with more severe learning disabilities, though liable to the same stigma of incompetence, are less able to appreciate the effect of their disability on their position in society and may therefore be less personally affected by it. However, the severity of their disability is such that they are unable to employ a 'cloak of competence'; their incompetence is plain and affects their interpersonal relations with all who come into contact with them.

The historical development of separate specialised services for people with learning disabilities has served to remove people with learning disabilities from view in general society. Mainstream service providers have become ignorant of the needs of this group, because they have been able to leave their care to 'specialists'. This ignorance, created by lack of exposure to people with learning disabilities, has tended to result in a workforce that, at least, lacks confidence in providing services to these patients and, at worst, may fear them.

The stigma of incompetence, which led to the removal of people with learning disabilities from society, still impedes access to health services because of the lack of expertise among the mainstream health care workforce that prior policies have created. However, our review identified no research that addressed the issue of stigma and related this to barriers experienced by people with learning disabilities in gaining access to mainstream health services.

### ***Information***

The need for information was apparent across all parties involved in accessing or providing health services to people with learning disabilities. There was no evidence as to whether accessible information about service availability is provided to people with learning disabilities or their carers. The little we learned about information was in relation to cervical screening; this suggested that no adaptation to usual procedures was made by practice staff to try to communicate about the service. Through our contacts with learning disability health services, however, we are aware that some individual practices and primary care trusts are making more appropriate information available to women about this service. However we found no such information initiatives in relation to health services more generally, nor did we find any evaluation of the effectiveness of any materials developed.

At the general practice level there appeared to be a lack of information about learning disability generally, and about the additional health problems that affect people with learning disabilities, particularly in relation to some syndromes. It is unclear to what extent GPs are providing a co-ordinating role for the multiple health service contacts

accessed by the people registered with them who have learning disabilities, even though they would seem ideally placed to do so.

The multiple health needs of some people with learning disabilities often require contact with specialists at more than one hospital. Consultation with parents suggested that there were problems associated with hospitals sharing information, for reasons of confidentiality. Repetition of investigations already carried out in another setting appears to be a risk associated with accessing continuing health care from multiple providers. However, the introduction of the new central electronic NHS record, between 2006 and 2008 (Department of Health, 2003), has the potential to make this type of duplication a thing of the past.

### ***Physical attributes of health premises***

The Disability Discrimination Act 1995 requires public service providers to remove, or provide alternative routes through, barriers which impede people with disabilities in using services. However, apart from a very thorough survey and report on barriers apparent in NHS facilities across the country, we found little evidence to suggest that these organisational factors have been fully explored or ameliorated. Provision of alternative means by which people can gain physical access to premises and communicate with service personnel is a minimum condition for accessing any service and therefore needs to be monitored.

### ***Staffing***

A number of issues relating to health care workers, referred to in the literature, need greater exploration. As with the research on barriers to GP care that in turn affect appropriate referral, negative attitudes due to stigma, lack of knowledge and interpersonal skills, and problems of continuity in relationships across the full range of mainstream health care professionals are apparent. For example, among 'front of house' staff, such as receptionists or porters, these factors might affect access to an appropriate appointment, or the way people with learning disabilities are directed on larger campuses. Among nurses, lack of knowledge and interpersonal skills in relation to learning disability may affect management of these patients while waiting to access A&E or specialist health care provision. Among both general and specialist health practitioners, these factors may affect identification of health need and referral to an appropriate health service. However, apart from identifying that these factors affect access, the literature did not fully explore how or why this is the case. There is no evidence of systematic attempts to tackle these issues across the full range of the mainstream health service workforce.

### ***Health economics***

Improved access to services is likely to result in greater demand and thereby act as a drain on financial resources. It is unclear however whether, given improved access, the high levels of unmet need presently identified would be maintained in the long run, or whether they merely reflect a 'health backlog' due to past difficulties in identifying need and seeking health advice.

Improvements in identification of need and help seeking are likely to result in more timely health interventions, precluding the need for more expensive acute health services when health complaints have deteriorated. Health economics could model the likely effects of improved access through dealing with the 'health backlog', and the subsequent trade-off between increased financial demands due to improved primary and preventive health care, and savings made through reduced demand for more expensive secondary health services. Gains of a less material nature, in terms of improved quality of life for the person with learning disability, should also be taken into account, as well as the reduction of burden for carers that improved health would bring.

### ***Innovations***

The literature demonstrated that many of the issues relating to unmet need, and the problems in identifying that need, have been known for more than 15 years. A range of local initiatives and interventions have been implemented that aim to improve health by facilitating equitable, timely, and efficient health care. However, comprehensive and rigorous evaluations, essential for the dissemination of good practice, are rare. Below, a range of means by which improvements in access to health care for people with learning disabilities may be achieved are considered.

#### ***1 Education***

Arguably one of the most effective ways to ensure that people with learning disabilities appropriately access health care must be the provision of education about symptoms and well-being. However, there appears to be no systematic study of the availability or appropriateness of health education to people with learning disabilities, or their carers.

Many of the studies on GP care suggested a need for information or training on learning disability and associated health conditions. However, those same studies often noted resistance by GPs to formal training programmes. Research is needed into the most acceptable and effective way of providing this knowledge. Other health workers and professionals may also benefit from undergraduate and in-service education regarding learning disabilities and associated health conditions. However, no specific initiatives appear to have been implemented in this regard.

**2    *Health checks***

The most widely implemented innovation aimed at improving access to health care was the health check or screen. However, apart from one study, there is little evaluation of whether health checks ultimately result in access to appropriate services. Therefore, although health checks have been shown to be very successful in identifying unmet need, it remains to be shown whether they improve access to health care in the long run.

**3    *Information management***

The importance of information management emerged in the literature. Having an accurate register of patients with learning disabilities should facilitate provision of appropriate primary care; efficient collation of information regarding health information from a variety of services should assist in appropriate review and further diagnoses; and possession of an individual, hand-held record of health need, preferred communication style and challenging behaviours should result in more appropriate interaction between patient and health professional, which ultimately aids accurate diagnosis and referral. However, there was no literature on information management as a means to improve access to health care.

**4    *Communication aids***

Other aids to accessing health care were identified from the literature and from contacts consulted in the study. Communication aids – for example, books to help locate symptoms on the body or identify medical equipment that might be used in a consultation – have the potential to improve access to health care by improving communication between more able patients with learning disabilities and health professionals. However, the research on the effectiveness of such tools is currently poor. Consultation also made it clear that learning disability health professionals currently facilitate access to health care for many people with learning disabilities, but their success does not appear to have been evaluated. Nor is it clear, within the recent policy directives on using mainstream rather than specialist services, what the future role of these professionals is likely to be.

### ***Conclusions***

This evidence base provides a foundation for future research into the barriers to accessing health care and into the types of innovations and initiatives that could help overcome these barriers. The research reviewed here has shown how barriers to appropriate and timely access to health services can operate outside, as well as within, the formal health care system. However, the fact that some difficulties are encountered prior to first contact with health services staff does not necessarily mean that health service providers are unable to influence them. Interventions such as appropriately designed health education programmes for people with learning disabilities and their carers (both paid and family) could have a positive impact on decision making about whether and when to seek formal health care. Similarly, the literature has highlighted the difficulties that people with learning disabilities often have in identifying and communicating symptoms and needs for health care interventions. Proactive approaches to identifying health needs, such as routine health checks, could help to overcome these barriers. Furthermore, routine health checks could also provide the basis for individual Health Action Plans and facilitate referrals to appropriate continuing and specialist health services.

The literature review has identified major evidence of substantial unmet health needs among people with learning disabilities. It remains unclear whether mainstream NHS primary care, optician, dentistry, nursing, therapy and specialist health services are currently equipped to deal with either the nature or the scale of the demands for health services which are suggested by this evidence of unmet need. However, it is also unclear whether these high levels of unmet need reflect a 'backlog' that has arisen because of the multiple barriers to access that people with learning disabilities have historically experienced and continue to experience. Research is therefore urgently needed into the impact of implementing initiatives and innovations to improve access over a long-term period to establish whether, once initial 'backlogs' of health need are addressed, levels of need and demands on mainstream health services approach wider population norms.

Recent policy (Department of Health, 2002) has proposed the new role of 'health facilitator' and the introduction of Health Action Planning to improve access to, and the use of, mainstream NHS services by people with learning disabilities. The evidence reviewed here has identified a number of areas where these new roles and functions could be targeted. For example, the role of 'health facilitation' could be extended and explicitly undertaken by family and paid carers, social care and education staff, as well as NHS staff. Specialist learning disability health professionals may have a particularly important role in facilitating the adaptation of mainstream services to meet the needs of people with learning disabilities, as well as helping to facilitate access to health care by individual people.

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Recent governmental initiatives outlined in the NHS Plan (Department of Health, 2000), aim to improve patient involvement within health services. However, it is not clear how programmes, such as the Expert Patient Programme, Patient and Public Involvement Forums, and the Choice and Responsiveness Consultations, intend to include people with learning disabilities as participants. These patients are likely to be among the most challenging to design services for and deliver services to. Their participation in initiatives of this type can prompt service improvements that will benefit people with a range of similar disabilities. However, inclusion also requires recognition that proactive and supportive approaches are required to ensure that the views and experiences of such groups are heard.

## ***4.5 Key findings***

- People with learning disabilities have problems identifying and communicating health need which affects approaches to health services.
- Carers have problems recognising signs and symptoms of illness in the people with learning disabilities they care for, particularly where deterioration is gradual and over the longer term. It is often carers, rather than patients themselves, who make decisions about when it is appropriate to seek health advice.
- Physical access difficulties, lack of communication aids (including competent, consistent translation services), and notices and signs in NHS premises affect access to mainstream health care for people with learning disabilities.
- People with learning disabilities under-use GP and dental health services given their levels of health need.
- Communication and examination difficulties, as well as time constraints, affect provision of primary care; this can have the consequence of also barring access to appropriate specialist or continuing health care services.
- Some GPs lack knowledge about learning disability generally and conditions associated with specific syndromes. They also sometimes lack information on specialist services available to these patients.
- Difficulties are apparent in accessing mental health care because carers and entry-level professionals sometimes interpret symptoms and signs of mental ill health as an aspect of the person's learning disability (overshadowing).
- Access difficulties are exacerbated by confusion over the relative roles and responsibilities of mental health as opposed to learning disability health services.
- Mainstream health care workers and professionals are perceived by some people with learning disabilities and their carers to have negative attitudes towards these patients.
- Health checks are successful in overcoming barriers to accessing health care raised by problems in identifying health need and deciding whether to seek health advice.

## **4.6 Key areas for further research**

- Research to improve identification of health need among people with learning disabilities:
  - to investigate health concepts among people with different levels of learning disability
  - to investigate help-seeking decision making by people with learning disabilities and their carers
  - to develop health education and communication aids to facilitate health need identification and communication by people with learning disabilities and their carers
  - to investigate the role of professionals in daily or regular contact with people with learning disabilities, such as school nurses, teachers and social carers, in identifying health need and facilitating access to health care.
- Research into changes in the organisation of health care:
  - to ensure the recommendations of the Disability Discrimination Act 1995 have been fully implemented with regard to physical changes and provision of communication aids for people with additional sensory impairments
  - to better meet the information needs of people with learning disabilities and their carers including information about services available, and signs and notices in health care settings
  - the effectiveness of measures to accommodate the special needs of people with learning disabilities and their carers when attending health premises, such as flexible appointment systems and separate waiting facilities for those for whom standard waiting areas are inappropriate
  - the success of health checks in providing evidence for health action planning and supporting access to mainstream health services.
- Research into health care delivery to ensure people with learning disabilities 'gain access' to services:
  - to develop effective and acceptable ways of providing information on learning disabilities, associated health conditions and specialist services to health professionals
  - to develop appropriate undergraduate and in-service training on working with people with learning disabilities to improve expertise and confidence
  - to investigate the role of learning disability health professionals in supporting mainstream colleagues in providing accessible health care to people with learning disabilities.

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- Research into ways to support people with severe and profound learning disabilities to access appropriate mainstream health care services and to develop complementary schemes where standard mainstream provision cannot be accessed.
- Research into access to health care for subgroups of people with learning disabilities including:
  - people with learning disabilities from ethnic minorities
  - people with learning disabilities living in segregated settings
  - older people with learning disabilities
  - children with learning disabilities.
- Research into access to dentists, opticians and audiologists.
- Research into access to A&E and continuing health care services.

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## **Appendices**

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### Appendix 1 Researcher and health professional contributors

Organisations initially contacted:

- British Psychological Society
- Royal College of General Practitioners
- Royal National Institute for the Deaf.

The following individuals responded and provided information, further contact names or discussed issues with the lead researcher:

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<i>National Development Team</i>	Jo Maughan, Margaret Flynn, Libby Kitt
<i>British Institute for Learning Disabilities (BILD)</i>	John Harris
<i>Brothers of Charity Services</i>	Susan Cartwright
<i>Foundation for People with Learning Disabilities</i>	Ruth Le Sirge, Hazel Morgan
<i>MENCAP</i>	Brian McGinnis
<i>Disability Rights Commission</i>	Vivienne Stone, Jill Stewart, members of the LD Action Group via Mark Shrimpton
<i>Royal National Institute for the Blind (RNIB)</i>	Gill Levy
<i>Values into Action</i>	Margaret Peirce
<i>North West Training &amp; Development Team (NWTDT)</i>	Janet Cobb
<i>Royal College of General Practitioners Learning Disabilities Working Group</i>	Graham Martin
<i>Royal College of General Practitioners Research Intelligence</i>	Fenny Green
<i>Wigan &amp; Leigh Social Services Department</i>	Cath Lane
<i>People First (Wales)</i>	Facilitated by Clive Ware

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### ***From the Cradle to the Grave***

Individuals initially contacted who contributed (academic/researchers and practitioners):

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Professor James Hogg	University of Dundee
Colin Beacock	Royal College of Nursing
Stuart Cummella	University of Bristol
Dave Hanson	Learning Disability Nurse, Bolton PCT
Chris Hutchinson	Learning Disability Nurse, Primary Care UK CNLD Network
Maria Jervis	Welfare worker, Sale & Altrincham MENCAP
Brian Kelly	Regional Director of Services, Brothers of Charity Services
Robert Macfarlane	CNLD, Scotland
Jo Maughan	National Development Team
Dr Duncan Mitchen	University of Salford, Department of Nursing
Peter O'Neill	Sale & Altrincham MENCAP
Scilla Reed	Speech & Language Therapist Brothers of Charity Services
Dr Jackie Rodgers	Norah Fry Research Centre, University of Bristol
Preet Sandhu	Research & Development Worker, Rochdale
Bridget Whittell	Research Officer, Wigan & Leigh PCT

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## ***From the Cradle to the Grave***

Contacts from research registers/research in progress and learning disability nursing networks

The following people responded and/or sent information for inclusion in the review:

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Professor Alastair Ager	Dr Lorraine Noble
Ms Elaine Allan	Mr Tony O'Sullivan
Dr Ruth Balogh	Ms Liz Piper
Ms V. Bliss	Ms Lisa Poynor
Dr Nick Bouras	Dr Jacqueline Rodgers
Mr Andrew Bratt	Ms Michelle Sergison
Ms Jennifer Brodie	Mr A Shaw
Professor Martin J. Brodie	Ms Moira Speechley
Miss Sally Broughton	Miss H. Stone Pearn
Mrs F. Bryan	Professor Gregory Stores
Mrs Joan Charlett	Dr André Strydom
Ms Mandy Chivers	Professor Eric Taylor
Professor Charlotte Clarke	Ms Karen Thomson
Dr Jennifer Clegg	Ms Cynthia Thornton
Dr Stuart Cumella	Mrs Jillian Turner
Dr Karen Dodd	Professor L. Weaver
Mr Frank Earley	Mr Christian Fluet
Ms Patricia Finnegan	Mr Matthew Gough
Mr Ivan Freer	Mr Dave Hanson
Mr Wilson Goodfellow	Ms Elizabeth Hensel (née Perkins)
Professor Gordon Grant	Professor James Hogg
Mr Dougal J. Hare	Dr Glyn Jones
Professor Sheila Hollins	Dr David Martin
Ms Maria Hurman	Ms Ghazala Mir
Mrs Christine Hutchinson	Professor A. Nicol
Dr Cath McGrother	Dr Rob Riemsma
Mr Peter Martin	Mr Dermot Rowe
Dr Zenobia Nadirshaw	Ms Glynis Whitehead

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## Appendix 2 Information requests to researchers and professionals

### ***Copy of contact letter***

Dear

***From the Cradle to the Grave. A literature review of access to health care for people with learning disabilities across the life span***

We have recently been funded by the Service Delivery and Organisation R&D programme of the Dept of Health to conduct the literature review above. We are, of course, keen to identify as much of the relevant literature as possible but as keyword searching of relevant electronic databases is notoriously problematic we have decided that, in order to be thorough in our searching, we should also contact researchers whose recent work may have addressed issues in accessing health care for people with learning disabilities for help. I have enclosed two documents which describe the model we are working to and the issues we hope to address through the literature.

We understand that you recently undertook a study entitled:

Would you please let us know if your study addressed 'access' to health care for this group. If it did we would be grateful to receive a copy of any related publications from this work, or details on how we might obtain a copy. If not, would you please return the 'Not Applicable' slip enclosed for our records.

We are also keen to hear of publications (papers, reports etc) that you feel should be included in the review, or other researchers who you feel we should contact in relation to this work. FREEPOST envelopes are enclosed for your convenience.

Your time and assistance with this review is greatly appreciated and will be acknowledged.

Yours sincerely

Alison Alborz  
Research Fellow

***Reply slip***

To:

Angela Swallow – Research contacts co-ordinator  
National Primary Care R&D Centre  
University of Manchester

Researcher:

Project:

Sorry, our research did not address issues relating to access to  
healthcare for people with learning disabilities.

Signed: .....

## Appendix 3 Discussion guides

### ***3.1 Discussion group – People with learning disabilities***

#### **Warm up**

##### ***Introductions***

Everyone says their name.

What are the names of the people (staff) who come to the house to help look after everything?

Everyone says what their job is.

Who was the first to come and live here at \_\_\_\_\_?  
Who came to live here last?

Who is the oldest?  
Who is the youngest?

#### **Purpose of visit**

- ☐ Collecting information about seeing the doctor, dentist or optician (for your glasses).
- ☐ Collecting information about going to the hospital for a check-up or to stay while you are ill.
- ☐ Is everyone happy to talk about these things?
- ☐ What you say will not be told to your doctor, dentist or any other health worker you talk about.
- ☐ What you say will be used to help doctors, nurses, dentists and all the other health workers do a better job.
- ☐ Can we use this tape recorder to help us remember everything you say?
- ☐ When we finish we will give you £15 in an envelope as wages for helping us. We will ask you to write your name on a piece of paper to show that you have had your money. This paper is for the University so that they know that we have given you the money.
- ☐ If we use words you don't know please tell us and we will say it another way.
- ☐ Does anyone want to ask us anything before we start?

## **Questions about health – discussion guide**

### ***Scene setting – context***

Let's talk about what happens when you feel poorly.

What makes you feel like that?

What happened the last time you were poorly?

Have you taken any medicine this week?

Do you take this medicine every day? (or just this week?)

Since you have lived here at \_\_\_\_\_

### ***What do you do when you feel poorly?***

(take some action)

What would you do next?

Does that make you better?

If you still feel bad, what would you do?

(tell someone)

Who do you tell? Staff? Family member? Another housemate?

Do you tell that person right away?

Do you wait until the person comes to the house and then tell them?

What do they do?

Does that make you better?

### ***Who decides whether you should go to see a doctor?***

What happens then? What if you don't agree?

Is your doctor's office near this house?

Do you all go to the same doctor's office/health centre/clinic?

Do you all see the same doctor there?

How do you get there? Is it easy or hard?

Does someone go with you?

## ***From the Cradle to the Grave***

### ***What happens when you arrive at the doctor's?***

What do you do?

What is the person on the desk like? (helpful/friendly/easy to understand?)

Does (the worker) go in with you when it's your turn to see the doctor?

What do they do then? Does that help? What would help more?

Who does the doctor talk to you when you go in?

What does s/he say to you? (Does s/he tell you what s/he thinks is the matter and ask before doing an examination/using equipment doing blood pressure etc?)

Is your doctor helpful/friendly/easy to understand?

What would make visiting the doctor easier/better?

### ***Have you been to the hospital?***

*(If none with experience)* Why do people have to go to the hospital sometimes? What is it like in a hospital? What would you say if someone said you need to go to a hospital? Who would help you get there? How should they help you?

(Did you have to stay there and sleep there?)

What did you go there for? Have you been to hospital for tests?

How do you get there? Was it easy or hard?

Did someone take you?

What happened when you arrived at the hospital?

What did you do? Where did you have to go? Was it easy to find?

What was the person on the desk like? (helpful/friendly/easy to understand?)

What would help?

Did (the worker) go in with you when it was your turn to see the doctor/specialist?

What happened then? Did that help? What would help more?

Who did the doctor talk to when you went in?

What did s/he say to you? (Does s/he ask before doing an examination/using equipment doing blood pressure etc?)

Was this doctor/specialist helpful/friendly/easy to understand?

What would make visiting the hospital easier/better?

## ***From the Cradle to the Grave***

### ***What is it like when you go to have your teeth checked?***

How do you get there? Is it easy or hard?

Does someone go with you?

What happens when you arrive at the dentist's?

What do you do?

Is the person on the desk helpful/friendly/easy to understand?

Does (the worker) go in with you when it's your turn to see the dentist?

What do they do then? Does that help? What would help more?

Who does the dentist talk to when you go in?

What does s/he say to you? (Does s/he ask before doing an examination/using equipment etc?)

Is your dentist helpful/friendly/easy to understand?

What would make visiting the dentist easier/better?

### ***What is it like when you go for your glasses?***

How do you get there? Is it easy or hard?

Does someone go with you?

What happens when you arrive at the opticians?

What do you do?

What is the person on the desk like? (helpful/friendly/easy to understand?)

Does (the worker) go in with you when it's your turn to see the wo/man who tests your eyes? What do they do then? Does that help? What would help more?

Who does the optician talk to when you go in?

What does s/he say to you? (Does s/he ask before doing an examination/using equipment?)

Is your optician helpful/friendly/easy to understand?

What would make visiting the doctor easier/better?

### **3.2 Paid carers discussion group – guide**

Discussion centred around model and questions outlined in info provided before meeting. These are:

- **Is the person with learning disability able to identify symptoms of ill health and if so what do they do about it?**
  - Help seeking
  - Communication

#### **Questions**

- 1 What are the problems that the people you care for have in identifying symptoms of ill health?
  - 2 Do they report health problems to you or anyone else?
  - 3 What difficulties do they face in trying to communicate their symptoms to you or another person?
  - 4 Are there any strategies/aids they can use to help with identification or communication of their symptoms?
- 
- **How much is it left to a carer to identify signs of ill health in the person with learning disability and, when they do, at what point do they decide to seek help from health services?**
    - Help seeking
    - Knowledge of person with learning disabilities

#### **Questions**

- 1 What difficulties do you experience in identifying signs of ill health in the people you care for?
  - 2 What types of problems would you deal with yourself?
  - 3 What types of problems would you arrange help for?
- 
- **How easy is it to arrange and attend health consultations?**
    - Arrangement of appointment, transport

#### **Questions**

- 1 What are the barriers to arranging health appointments for the people you care for with GPs, dentists etc./therapists /hospital-based?
- 2 What are the difficulties in getting the person to their appointment?

- **What are the difficulties in using 'entry-access' health services (GP, dentist, optician, A&E, NHS Direct, walk-in clinic)?**
  - Aspects of the service that facilitate access
  - Aspects of the service that are a barrier to access
  - Helpfulness of health professionals in identifying additional health needs and referring on
  - Continuing unmet need
  - Health care resource allocation/rationing/equity

***Questions***

- 1 Are there physical barriers to using local GP etc. services? (prompt list)
- 2 Are there any services which have improved or made it easy to use their facilities? What helps?
- 3 What are the problems in consulting front-line staff (reception etc.) and health professionals in these services?
- 4 Do they address their questions to the person who has come for the consultation or their carer?
- 5 Are there health needs which are not being met by these services (e.g. access to equipment/aids, dental care)?
- 6 Are there any problems the GP won't deal with?
- 7 To the best of your knowledge are the people you care for referred on appropriately when needed?
- 8 Are you aware of any difficulties in gaining access to services available to other members of the general public? (e.g. screening – cervical, breast, CHD)
- 9 Are there difficulties using 'high-street' health care services such as dentists, opticians or the community pharmacy?
- 10 What are the difficulties in consulting dentists or opticians?

- **What are the difficulties in 'continuing access' to health services (full range of services including therapies, acute and planned admission to hospital etc.)?**
  - Aspects of the service that facilitate access
  - Aspects of the service that are a barrier to access
  - Helpfulness of health professionals in identifying additional health needs and referring on
  - Continuing unmet need
  - Health care resource allocation/rationing/equity

***Questions***

- 1 Are there problems in gaining physical access to community services such as physio, speech and language and occupational therapies?
- 2 Are there barriers to physically accessing services that are hospital based – as an outpatient or as an inpatient?
- 3 Are you aware of services that have specifically found ways to improve or made it easy to access to their facilities?
- 4 What are the difficulties in consulting front-line staff and health professionals in community services?
- 5 What problems to you experience in consulting hospital-based front-line staff and health professionals?
- 6 Are you aware of any health problems suffered by the people you care for which are not being catered for in an ongoing way?
- 7 Are there barriers to accessing specific treatments for the people you care for that are provided to other members of the general public?

### **3.3 Discussions with parents – guide**

- **Identifying ill health and seeking help**

#### **Questions**

- 1 What are the problems that your son or daughter has in identifying symptoms of ill health?
- 2 Do they tell you if they are not feeling well or are injured?
- 3 What difficulties do they face in trying to communicate their symptoms to you?
- 4 Are there any strategies/aids they can use to help with identification or communication of their symptoms?

- **Parent's role in identifying ill health and seeking help**

#### **Questions**

- 1 What difficulties do you experience in identifying signs of ill health in your son or daughter?
- 2 What types of problems would you deal with yourself?
- 3 What types of problems would you arrange help for?

- **Arranging and attending health consultations?**

#### **Questions**

- 1 What are the barriers to arranging health appointments for your son or daughter with GPs, dentists etc./therapists/ hospital-based?
- 2 What are the difficulties in getting them to their appointment?

- **The difficulties in using 'entry-access' health services (GP, dentist, optician, A&E, NHS Direct, walk-in clinic)**

#### **Questions**

- 1 Are there physical barriers to using local GP etc. services?
- 2 Are there any services which have improved or made it easy to use their facilities? What helps?
- 3 What are the problems in consulting front-line staff (reception etc) and health professionals in these services?
- 4 Do they address their questions to your son or daughter or to you?
- 5 Are there health needs which are not being met by these services (e.g. access to equipment/aids, dental care)?
- 6 Are there any problems the GP won't deal with?

## ***From the Cradle to the Grave***

- 7 To the best of your knowledge is your son or daughter referred on appropriately when needed?
  - 8 Are you aware of any difficulties in gaining access to services available to other members of the general public? (e.g. screening – cervical, breast, CHD)
  - 9 Are there difficulties using 'high-street' health care services such as dentists, opticians or the community pharmacy?
  - 10 What are the difficulties in consulting dentists or opticians?
- **The difficulties in 'continuing access' to health services (full range of services including therapies, acute and planned admission to hospital etc.)**

### ***Questions***

- 1 Are there problems in gaining physical access to community services such as physio, speech & language & occupational therapies?
- 2 Are there barriers to physically accessing services that are hospital based – as an outpatient or as an inpatient?
- 3 Are you aware of services that have specifically found ways to improve or made it easy to access to their facilities?
- 4 What are the difficulties in consulting front line staff and health professionals in community services?
- 5 What problems to you experience in consulting hospital based front line staff and health professionals?
- 6 Are you aware of any health problems suffered by your son or daughter which are not being catered for in an ongoing way?
- 7 Are there barriers to accessing specific treatments for your son or daughter that are provided to other members of the general public?

## Appendix 4 Issues raised in discussion groups

### **Diagnosis**

Pain thresholds and tolerance of pain (perceptions of carers and staff – need to check paediatrics literature)

Parents as barriers to access to health care for the person with learning disabilities (due to lack of trust and belief in the treatment)

Overshadowing, third parties, criteria for seeking access

### **Education**

Health education and health needs assessment of carers

Education for parents (e.g. Makaton)

School – role of school pivotal, for SEN Statement Review, awareness of other staff (e.g. transport) of health issues

Integration into mainstream education, specialist school nurses role, triage

### **Legal framework**

Disability Discrimination Act (particularly relating to physical access to NHS premises), Children's Act

### **Workforce issues**

Attitudes, knowledge, beliefs, training of health care staff (about learning disabilities). Variation in staff behaviour – extremes – jobsworth – conflicts of interest (between staff and patients), arrogance, culture, hierarchies, competences, skills, confidence, authority, judgement, crisis, empathy, patient-centred care, shared decision making

Normalisation – i.e. what do you expect with a child with learning disabilities as a barrier to access?

Staffing levels/ratios/shortages (to enable person with learning disabilities to go to GP), issues affecting nursing workforce affecting learning disability nursing workforce?

Stigma – nurses refusing to label someone they suspect of having learning disabilities with learning disability and in doing so depriving them of potential access to services/support to access services

## **Communication issues**

Expectations, staff lacking experience and exposure to learning disability patients/users

GP receptionists – access to appropriate appointments depends on relationships/awareness

Assertiveness of parents/carers, articulate, determined

Constant need to repeat and/or disseminate information to professionals, need for hand-held or electronic notes

## **Health needs**

Referrals – including reluctance to refer to specialists

Staff awareness of difficulties of identifying needs in this group, particularly in relation to identification of pain

## **Continuity of care issues**

Barriers to developing trust and relationships necessary to identify health problems included use of temp./agency/bank nurses, internal staff hierarchies of management, staff not feeling empowered to act, having to defer and/or wait for weekly GP visit or nurse, prevarications between departments over who takes responsibility when person with learning disabilities enters hospital

Routine ward care – culture, trust

Use of private health care

Confidentiality, medical records (legal framework for sharing information from general and specialist care)

## **Home-from-home/respice care**

Procedure involved inhibits help-seeking behaviour, forms, social workers key for volunteers to access training

## **Quality of care issues**

*Time constraints* – for looking, listening, checking and observation of person with learning disabilities in general practice consultations, flexibility of services

*Inappropriate treatments* – medication not available in appropriate forms – medicines management issues; aids, equipment and appliances – assumptions that person with learning disabilities will not be able to operate them; issuing of 'do not resuscitate' notes and quality-of-life assumptions

## ***From the Cradle to the Grave***

*Secondary mental health care* – labelling between psychiatric services and learning disability services; primary/secondary care interface and partnerships, joined-up working

*Particular services* – dentists, opticians, NHS Direct, A&E, health visiting, community nursing, care pathways, liaison nurses, speech and language therapy services, physiotherapy services – disjointed delivery – move to integration leads to general rather than specialist support

Pain clinics

*Particular conditions* – dysphagia, weight loss, challenging behaviour, dementia

## Appendix 5 Search terms

### **Thesaurus searching**

The following searches were carried out with the terms exploded and applying subheadings where occurring:

- Medline & Cinahl
- (Learning Disorders or Mental Retardation) AND Health Services Accessibility
- Embase
- (Learning Disorder or Mental Deficiency) AND Health Care Access
- Psychinfo
- (Learning Disorders or Learning Disabilities or Mental Retardation) AND Health Care Utilization

### **Main search strategy**

Sample strategy is for OVID databases:

- 1 (learning disab\$ or learning disorder\$ or developmental\$ disab\$ or intellectual\$ disab\$ or mental\$ retard\$ or learning difficult\$ or intellectual\$ impair\$ or mental\$ handicap\$ or mental\$ subnormal\$ or mental\$ deficien\$).ti
- 2 (access\$ or advoca\$ or barrier\$ or carer\$ or communication\$ or information or parent\$ or uptake or utili#ation or need\$ or provision or consent\$ or help seeking or help-seeking).ti
- 3 1 and 2
- 4 (School nurse\$ or health visitor\$ or abuse or Alzheimer\$ or Down\$ or autis\$ or cerebral palsy or challenging behaviour or dementia or epilepsy or health promotion or hypo-thyroidism or hypo thyroidsim or mental health or prescrip\$ or screening or sensory impairment or hearing or vision or sexual health).ti.
- 5 4 and 1
- 6 5 or 3

### **Additional searches (all terms appearing in title only)**

- #1 AND (Utili#e or Inaccessib\$ or Availab\$ or Prohibit\$ or Affordab\$ or Applicab\$)
- #1 AND (Stress or Coping or Diagnos\$ or Pain or Overshadow\$ or Third Part\$ or Health education or Integrat\$ or Referral\$ or Trust or Confidential\$ or Medical record\$ or Volunteer\$ or Time or Labelling or Partnership\$ or Care Pathway\$)

## ***From the Cradle to the Grave***

- #1 AND (SEN Statement Review or Disability Discrimination or Children\$ Act)
- #1 AND (Workforce or labo#rforce or staff\$ or professional\$ or doctor\$ or nurs\$) AND attitude\$
- #1 AND (Continuity ADJ5 care or Routine ADJ5 care or Care ADJ5 interface)
- #1 AND (Private Health Care or Pain Clinic\$ or Dysphagia or Weight or Dentist\$ or dental or Optician\$ or optical or eye or NHS Direct or Health Visiting or Health Visitor or Community Nurs\$ or Liason Nurs\$ or Physiotherapy Receptionist\$)
- #1 AND (Speech ADJ5 Language)
- #1 AND (Casualty or (Accident ADJ Emergency))

## **Databases searched**

### ***Medicine/health***

- Medline (Index Medicus)
- Embase (Embase)
- Cochrane Library
- CINAHL (Cumulative Index to Nursing & Allied Health)

### ***Health service management***

- HMIC (Health Management Information Consortium)

### ***Social science***

- Social Science Citation Index
- ASSIA (Applied Social Science Index)
- IBSS (International Bibliography of the Social Sciences)
- CareData
- AgeInfo
- Sociological Abstracts
- PsychInfo

### ***Education***

- BEI (British Education Index)
- ERIC (Educational Resources Index)

***Grey literature***

- SIGLE (System on Grey Literature in Europe)
- ASLIB Index to Thesis
- ISI Index to Scientific and Technical Proceedings

**Additional sources consulted**

We searched the on-line library catalogues of the following organisations for the occurrence of learning disabilities in the title of documents:

- Royal College of Nursing  
<http://rcn-library.rcn.org.uk/uhtbin/cgiirsi/Friday+May++3+13:22:57+BST+2002/0/49>
- Royal National Institute for the Blind  
<http://www.rnib.org.uk/library/research/>

We searched the web sites of the following organisations:

- SCOPE: <http://www.scope.org.uk/>
- RADAR:  
<http://www.radar.org.uk/RANE/Templates/frontpage.asp?lHeaderID=227>
- Down's Syndrome Association: <http://www.dsa-uk.com/>

## Appendix 6 Literature selection criteria

Topic	Inclusion criteria	Exclusion criteria
<b><i>Wider determinants of health</i></b>		
Health education/ promotion services	<ul style="list-style-type: none"> <li>• Access to health education</li> <li>• Access to health promotion</li> </ul>	<ul style="list-style-type: none"> <li>• Effectiveness of health education</li> <li>• Nature of health promotion</li> </ul>
<b><i>Specific issues:</i></b>		
Sexual health	Access to sex education that addresses sexual health	Sex education focusing on sexuality, relationships and contraception without emphasis on disease prevention
Provision of patient information	Access to services, services available	Information on treatment or service per se
Screening	Access to screening	Nature/effectiveness of screening programmes
<b><i>Identification of need</i></b>		
Individual level	<ul style="list-style-type: none"> <li>• Communication of health need</li> <li>• Self-advocacy/help seeking in seeking health care</li> </ul>	<ul style="list-style-type: none"> <li>• Descriptions/ effectiveness of programmes to improve communication effectiveness</li> <li>• Participation on user panels</li> <li>• Effectiveness of training</li> </ul>
Parent/carer level	<ul style="list-style-type: none"> <li>• Identification of health problem</li> <li>• Stress and coping</li> <li>• Practical support in accessing primary/ continuing health care</li> <li>• Interactions with health professionals</li> </ul>	Carer as therapist
Identification of sexual abuse	Facilitation of access to health care for effects of sexual abuse	Problems with identification of sexual abuse and support to individuals/reporting to police
GP/front-line staff	<ul style="list-style-type: none"> <li>• Role in accessing secondary/ continuing care – referrals</li> <li>• Role in referral to other specialists</li> </ul>	<ul style="list-style-type: none"> <li>• Effectiveness of treatment/drug</li> <li>• Nature/effectiveness of screening programmes</li> </ul>

Topic	Inclusion criteria	Exclusion criteria
<b>Identification of need</b> <i>(continued)</i>		
Identification of learning disabilities	Where diagnosis facilitates access to appropriate health care	Focus solely on learning disabilities
Challenging behaviour	Where aspect of health condition	Where communicating social needs
<b>Organisational determinants</b>		
	<ul style="list-style-type: none"><li>• Geographical issues</li><li>• Availability of transport</li><li>• Availability of appointments</li></ul>	
<b>Entry access health services</b>		
	<ul style="list-style-type: none"><li>• Staff attitudes/ knowledge inhibiting access</li><li>• Communication/ relationship with person with learning disability and carer</li><li>• Setting practices/ routines forming barrier to access</li><li>• Consent – barrier to treatment</li></ul>	<ul style="list-style-type: none"><li>• Content of training programmes</li><li>• Assessing capacity/ testing</li></ul>
<b>Continuing access health services</b>		
	<ul style="list-style-type: none"><li>• Staff attitudes/ knowledge inhibiting access</li><li>• Communication/ relationship with person with learning disability and carer</li><li>• Setting practices/ routines forming barrier to access</li><li>• Consent – barrier to treatment</li><li>• Access to health services for social reasons – fertility regulation</li></ul>	Assessing capacity/testing
<b>Innovation</b>		
	Outcomes of specific programmes, organisational developments to improve access to health services	How to – descriptions of method

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## Appendix 7 Data extraction pro forma

**Study evaluation**      Reviewer ID

---

Author(s)

Title

Source

Year

Final rating

**Study type**                      **Original research** **Report** **Review** (add appropriate refs only)

---

Does the paper meet the initial inclusion criteria?                      **Yes/No**

If **No** – reason

If **Yes** – proceed to quality evaluation

Refs checked?

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### Study design

The study design is: **quantitative** **qualitative** **mixed** (circle one)

Study aim:

Paper aim (if different):

Sample

Instrument(s)

Instrument appended?

**Yes/No**

## From the Cradle to the Grave

### Primary quality indicators

Are the aims of the study/paper clear?	Yes/No
Is the study design appropriate to the aims of the paper?	Yes/No
Is the context or setting adequately described?	Clear/Partially described/Unclear
Is the sampling adequate to explore the aims?	Yes/Unclear/No
Is data collection technique adequately described & rigorous?	Yes/No
Are data analysis techniques adequately described & rigorous?	Yes/No

**Area(s) of model** explored by this paper (use in conjunction with guide):

		Code(s)		
<input type="checkbox"/> <b>Wider determinants of health</b> (screening/health promotion)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="checkbox"/> <b>Identification of need</b> (personal/third party)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="checkbox"/> <b>Organisational determinants</b> (physical/organisational access)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="checkbox"/> <b>Entry access</b> (first contact health services attitudes/practices/skills)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="checkbox"/> <b>Continuing access</b> (second or more contact health attitudes/practices/skills)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="checkbox"/> <b>Innovation</b> (initiatives designed to improve access)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

#### Age group

**1** Pre-school **2** Primary school **3** Adolescent (to 18) **4** Adult **5** Older adult (60+)

#### Disability range

(Mild/moderate/severe/profound)

**If area has high volume of research and above indicators show paper lacking quality end assessment here.**

For 'quality' or low volume papers proceed with assessment based on study design:  
Criteria A – Quantitative; Criteria B – Qualitative; Criteria C – Both those above + supplementary criterion

## ***From the Cradle to the Grave***

### **Key findings**

#### ***Criteria A – Quantitative***

##### **Key findings**

- 1 Findings emerging connect with existing bodies of theoretical knowledge or generate new understanding

*Yes/Unclear/No*

- 2 Does confounding offer an alternative explanation to the findings?

☐ Confounders controlled?

☐ Control adequate?

☐ Any uncontrolled confounders?

☐ Confounders taken into account in interpretation?

☐ Outcome generalisable?

☐ Justified conclusion

- 3 Policy relevance:

Extent addresses issues of concern to practitioners and policymakers

*Spot on 1 2 3 4 5 Not at all*

Extent to which it empowers service users

*Spot on 1 2 3 4 5 Not at all*

**4 Using information given above rate studies as follows:**

- |     |   |
|-----|---|
| I   | Little confounding or confounding controlled or large sample used. Data collected contemporaneously. Knowledge indicator met.               |
| II  | Main confounders partially controlled or shown to be low level. Wide evidence base and knowledge indicator met                              |
| III | Confounders not controlled or measured, or measured and found moderateInvolves specific service or opinion only but knowledge indicator met |
| IV  | Main confounders operating or likely to be involved. A single service and very small sample or knowledge indicator not met                  |

***Overall quality rating***

## ***From the Cradle to the Grave***

### ***Criteria B – Quantitative***

#### **Key findings**

- 1 *Themes* emerging connect with existing bodies of theoretical knowledge or generate new understanding (illuminates subjective meaning, actions and context)

*Yes/Unclear/No*

- 2 Theoretical adequacy:

☐

Clear description (design responsive to circumstances – flexible)

☐

Analysis logical (different sources compared and contrasted)

☐

Imagination in interpretation (description, example, meaning, significance)

☐

findings coherent, fair, honest (reflexivity – effect of methods on findings)

☐

generalisable/transferable (features found in other cases)

- 3 Policy relevance:

Extent addresses issues of concern to practitioners and policymakers

*Spot on 1 2 3 4 5 Not at all*

Extent to which it empowers service users

*Spot on 1 2 3 4 5 Not at all*

## ***From the Cradle to the Grave***

**Primary focus** is the extent to which studies add to existing, or generate new knowledge

### **4 Studies rated as follows:**

- |     |  |
|-----|--|
| I   | All or most indicators met.                                |
| II  | Main quality indicators met including knowledge indicators |
| III | Some lack of details but meets knowledge indicators        |
| IV  | Some lack of details including knowledge indicators        |

***Overall quality rating***

## ***From the Cradle to the Grave***

### ***Criteria C – Mixed studies***

#### **Fill out A + B**

#### **And consider**

- 1 Does the study adequately meet the quality criteria for its quantitative and qualitative parts?

Yes/Mostly/Not really

- 2 Are the two parts to the study adequately integrated?

Yes/Somewhat/No

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If 1) and 2) met give combined quality rating:

***Combined quality rating***

## Appendix 8 Studies included in the review

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
82 McGrowther <i>et al.</i> , 2002	2	Quantitative	All South Asian and white adults (20+) known to the Leicestershire ID register (n=2256) and from latest interviews (n=2540, including 206 SA 22334 white). Interviews carried out in person's home with main carer (in preferred language) between 1987 and 1998 – 90% between 1992 and 1998. SA = Indian, Pakistani or Bangladeshi born in Indian subcontinent, East Africa or UK. White = British, Irish or other European exc. West Indian and other minorities.	Adult	All	<ul style="list-style-type: none"> <li>Lower access to psychiatrists for SA people with learning disabilities (Id) compared to whites.</li> </ul>
195 Leahy <i>et al.</i> , 1986	3	Quantitative	146 children ages 6–7 or 11–12 in 5 health districts in NW region. 109 families interviewed (75% response rate), 73 in districts providing the routine dental services, 36 in districts providing a 'developed service'.	Primary school	Severe/profound	<ul style="list-style-type: none"> <li>Maternal anxiety related to accessing dental care. Reasons: unpleasant for child; difficulties in waiting room; need to explain handicap</li> </ul>
211 Purcell <i>et al.</i> , 1999	3	Quantitative	24/42 carers who expressed interest in project after info sent out to all local facilities. 88% female, 13 residential and 11 day-service staff – managers and frontline staff. Length of service 1–14 years, 40%+ had formal nursing, social work or educational qualifications. 140 people with Id identified as having communication problem (35% total service population). Key workers completed postal questionnaire giving further info: 104 replies (72% response rate), 28 clients selected to partner staff volunteers but ensured sample representative (4 staff worked with 2 clients each). Consent sought and no refusals. 57% male, mean age 41, 77% in group or own home, 71% in day services. 53% supervision or assistance with self-care, 36% mobility problems, 43% behavioural problems, 18% used sign system, 89% judged capable of using and understanding speech, 71% successful communication with known people, 7% always unsuccessful.	Adult	All	<ul style="list-style-type: none"> <li>Problems identifying non-verbal communication</li> <li>Carers underestimated hearing difficulties</li> <li>Carers overestimated ability to understand verbal language</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
299 Moss <i>et al.</i> , 1993	2	Quantitative	105/110 people with Id identified in the borough. Interviews with people with Id and carer – 51 pld judged to have sufficient language to respond to questions and enable assessor to make confident ratings. 14 additional cases proceeded to 'core PAS items but degree of confidence in subsequent ratings low.	Older adult (50+)	All	<ul style="list-style-type: none"> <li>Carers aware symptoms but tended not recognise them as indicating mental illness or in one case was unable to decide whether merited referral to the GP</li> </ul>
575 Nadler <i>et al.</i> , 1991	3	Quantitative	25 couples of children aged 5 to 12 with moderate/mild Id. Mean age parents 40 (24–59), all urban middle class. Sample obtained via government-sponsored child clinic where children receive periodic check-ups. 40 families contacted (63% response rate). Refusals more likely to come from lower socioeconomic groups.	Primary school	Mild/moderate	<ul style="list-style-type: none"> <li>Parents with higher levels of education more likely to seek help for health problems</li> </ul>
850 Bambrick <i>et al.</i> , 1991	3	Quantitative	274 households in Nottingham Health District identified from survey of service usage in district which ID 374 (100 of these not usable due to missing data or lack of consent to use data for future research). Questionnaires obtained from 138 households (50% response rate). No significant differences between response and non-response based on demographic data held. 62 household returned 2 questionnaires (out of 222 two-parent households), 59 single, 5 joint questionnaires. 90% of people with Id attending schools or training centres for people with severe Id, 10% schools for people with moderate Id.	Adolescent/ young adult	Severe	<ul style="list-style-type: none"> <li>84% of parents felt they alone or in conjunction with familiar doctor should have power to consent for non-medical sterilization</li> </ul>
906 Howells, 1986	2	Quantitative	151 trainees, full range handicap, 96 residential home, 29 lodgings, 19 SSD hostel, 7-hospital type accommodation. Ages: 5 <24; 50 25–34; 45 35–44; 24 45–54 ; 14 55–64; 13 65+. No details of carers.	Adult	All	<ul style="list-style-type: none"> <li>Help not sought for 'trivial' complaints</li> <li>Parents embarrassed by behaviour when vision surgery reluctant to access</li> <li>Communication barrier to proper medical assessment by GP</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
1032 Mansell <i>et al.</i> , 1992	3	Quantitative	119 sexual abuse victims with Id. Recruited via sending questionnaires to advocacy groups, service agencies and sexual assault centres. Questionnaires completed by client advocates and victims with Id – in Canada and the US. 170 questionnaires returned between 1987 and 1990. (Other 51 questionnaires related to people with sensory and motor disabilities but no Id. This paper based on evidence from Id respondents only. No of questionnaires completed by third parties not revealed but considered in reporting. Age range 1.5 to 51 years, mean 20. 80% female offenders age range 14–80 years, mean 33. Victims 38 severe/profound; 42 mild /moderate; rest undetermined and excluded from analysis.	All	All	<ul style="list-style-type: none"> <li>Problems with the availability of health care for sexual abuse</li> <li>Greater difficulties the more severe the learning disability</li> <li>Services that were available were not adapted to the needs of this group</li> </ul>
1602 Davies <i>et al.</i> , 2001	3	Quantitative	99 women aged 50 years or more living in the community within the catchment of a single community care provider. 58 questionnaires returned (59%). Age range 52 to 90 years (6 over 65 and outside targeted age for National BC Mammography Screening Programme guidelines. No details on non-responders.	Older Adult(50+)	All	<ul style="list-style-type: none"> <li>Women with Id more often being omitted from GP lists of registered patients eligible for mammography screening</li> <li>Suggest due to GP assumptions regarding appropriateness of the service for women with Id</li> </ul>
1607 Webb <i>et al.</i> , 1999	2	Quantitative	People with Id resident in IHC facilities. 98% screened (1311). Age, gender, severity of learning disability breakdown not given.	All?	All	<ul style="list-style-type: none"> <li>73% of people with Id screened required health actions</li> <li>Most actions health promotion and some reviews of existing treatments</li> </ul>
1608 Barr <i>et al.</i> , 1999	3	Quantitative	People with Id in Down & Lisburn Health and Social Services Trust area. 373 people 20yrs+. 59% men. 20% with Down's syndrome. 124 randomly selected clients/carers (1:3). Response rate 60%.	Adult	All	<ul style="list-style-type: none"> <li>Substantial unmet need identified</li> <li>87% carers reported following up concerns and subsequent improvement in health</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
1841 Tiller <i>et al.</i> , 2001	1	Quantitative	29% random sample of adults (18–65) n=310 no substitution. 209 participated (response rate 67%). Non-respondent significantly more lived in community-run residential accommodation (Chi sq no value p<.05). More females 57%. Sample 62% lived in community. Mean age 38/9 (SD 11.6) but people in community tended to be younger (36.3, SD 11.5) than those in residential accommodation (43.2, SD 10.5).	Adult	Severe/profound	<ul style="list-style-type: none"> <li>People with Id living in the 'community' considered to have worse dental caries than those in residential accommodation</li> <li>Community participants less likely to see a dentist regularly</li> <li>Community participants more likely to have no dentist and to only seek care when having trouble</li> </ul>
1898 Lennox <i>et al.</i> , 2001	3	Quantitative	45 self-selected GPs from previously postal surveyed GPs (1000) randomly selected from Health Insurance Commission database. Characteristics of larger group representative of GPs generally. Each GP identified patients with Id (aged 19+) and 3 randomly selected by investigators to be approached for consent to participate. 15 GPs completed all components of study (drop-out rate 66%). 38 patients completed project (21 female, 17 male). 7 excluded because not Id. Age range 22–68, mean 40 years.	Adult	All	<ul style="list-style-type: none"> <li>Comprehensive Health Assessment is useful in increasing or clarifying GP awareness and providing opportunity to clarify and update aspects of care which may not be main responsibility but GPs can help to facilitate</li> </ul>
1974 Broughton <i>et al.</i> , 2000	3	Mixed	52/166 approached (45% response rate). Women aged 20–64 years receiving services from the Cambridgeshire Id teams. Women with severe Id excluded as well as 2 unable to respond verbally to questions about recent significant event in their life. 34 carers also interviewed. Initial contact by letter accompanied by info sheet explaining aims of study. 9 aged 20–29; 18 aged 30–39, 18 aged 40–49; 6 aged 50–59 and 1 60+.	Adult	Moderate	<ul style="list-style-type: none"> <li>37% women withdrawn from screening programme at request of GP</li> <li>75% women (inc. 37% of those tested) did not understand purpose; main reasons given – prevention of pregnancy; assist with pregnancy; stop menstruation</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
1984 Dovey and Webb, 2000	2	Quantitative	Random sample 250 GPs in Southern Region New Zealand. All 137 valid responses (65% response rate). Aged between 27 and 72, mean 42: 64.9% male, 75.9% full-time. Geographical distribution similar to that of region. Gender distribution suggests respondents similar to whole population of GPs.	All	All	<ul style="list-style-type: none"> <li>62% GPs saw selves as key providers of health care for people with Id in their community</li> <li>Tended not to favour a health promotion screening role</li> <li>Did not see regular hearing/sight testing as their responsibility</li> </ul>
2086 Bollard, 1999	3	Quantitative	Users of 12 practices (18+) in Coventry. 205 identified over 2 years but data for this study from first 18 months of operation involving 65 health checks. 39 men, 26 women (59% uptake), majority accompanied by carer or key worker. Ages ranged from 22 to 78.	Adult	All	<ul style="list-style-type: none"> <li>Awareness and understanding of people with Id by practice nurses and GP increased</li> <li>46% GPs more aware of health needs</li> <li>77% GPs more aware of specialist Id services</li> </ul>
2114 Allan, 1999	4	Quantitative	Attendee at two Adult Training Centres in Grampian Healthcare district. Clinics established at each Centre A analysis based on 30 consultations, 12 of which were carer consultations. Centre B based on 44 consultations, all people with Id.	Adult	All	<ul style="list-style-type: none"> <li>Each service user had health need identified</li> </ul>
2420 Bond <i>et al.</i> , 1997	3	Quantitative	1994: Gwent 125/242 GPs (51.7% response rate), 79% male, 91% ft work; med. age 46. 1995: west Gloucs 132/221 GPs (59.7% response rate), 71% male, 80% full-time work; med. age 42. Comparison of respondents with non-respondents revealed no significant differences in gender or number of years qualified.	All	All	<ul style="list-style-type: none"> <li>GPs felt responsible for the medical care of people with Id in community</li> <li>Many GPs in both areas against taking responsibility for health promotion and screening initiatives</li> </ul>
2615 Kerr <i>et al.</i> , 1996	2	Quantitative	242 GPs in Gwent, south Wales. 126 usable questionnaires All returned (response rate 52.1%). Comparison of respondents with non-respondents revealed no significant differences in gender or number of years qualified.	All	All	<ul style="list-style-type: none"> <li>GPs tended to agree responsible for medical care</li> <li>Generally opposed to organising health checks and assessing hearing and eyesight</li> <li>In favour of providing thyroid function tests to people with Down's syndrome over age 30</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
2636 Cambridge, 1996	4	Quantitative	115 service contacts made and 26 participated (response rate 23%); total of 26 service questionnaires and 34 user questionnaires. Users aged between 17 and 60, median 30, mean 27. 79% had good or very good verbal communication skills; 32% lived in family home, 41% in staffed or unstaffed housing, 2 in hospital, 2 in hostels.	Adult	Mild	<ul style="list-style-type: none"> <li>75% possibly having sex that put them at risk of HIV</li> <li>Suggests need for specialist service intervention around safer sex and education</li> </ul>
2649 Thornton, 1996	2	Qualitative	3/12 randomly selected practices with 4+ partners in one community trust area (25% response rate). Groups consisted overall of 6 GPs, 6 health visitors, 3 district nurses, 2 practice nurses, 2 admin staff and 1 other. 1 practice served mainly people in higher socioeconomic groups (III <sub>m</sub> and over), another mainly lower SE groups (III <sub>nm</sub> and under), the third an even spread over all groups.	Adult	All	<ul style="list-style-type: none"> <li>None had considered introducing a register</li> <li>2/3 considered may restrict numbers in interests of practice as a whole, due to insufficient remuneration to work with this group</li> <li>All positive invitation to smear test automatic</li> <li>Other screening required self-referral on basis of practice notices</li> <li>Minimal knowledge of or liaison with CTLDs</li> </ul>
2718 Whitfield <i>et al.</i> , 1996	2	Quantitative	Proportional random sample of 149 adults from register population of 919 patients aged 20 years+. Register regularly updated but known to be inaccurate; however, contained large proportion of people with Id in the health district under study. Proportional stratification, sex and type of accommodation, used to match sample to register distributions on these variables. 127 people with Id contactable/appropriate for study. 90 allowed access by carer/professional. 62 GPs of 78 people with Id agreed – response rate 93% (62/67). 47 male and 31 female patients. 12 female GPs, age distribution a little older than population of GPs in Avon.	Adult	All	<ul style="list-style-type: none"> <li>No difference in number of consultations over 12 months between people with Id and control group</li> <li>Differences in type of health problems detected</li> <li>Evidence of more preventive assessments for control group</li> <li>Report evidence suggests GPs attitudes may preclude them from considering preventive procedures</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
2804 Beange <i>et al.</i> , 1995	1	Quantitative	202/223 people with Id (90.6% response rate) randomly selected, stratified for age, gender and residence. 98 males, 104 females, 47% 20–27, 34% 30–39, 19% 40–49. 35% mild Id, 40% moderate, 14% severe, 11% profound. 29% institutional care, 31% group homes, 40% private accommodation (relatives/independent). 27% Downs. Used comparison groups from same geographical area (deprivation etc.) and same age group (general population survey).	Adult	All	<ul style="list-style-type: none"> <li>• Disease unrecognised by carers</li> <li>• More obese, exercised less and slept more than local population</li> <li>• 95% had medical conditions</li> <li>• 42% conditions previously undetected</li> <li>• 74% required specialist care but not all received it</li> <li>• Half conditions inadequately managed</li> <li>• 40% had 6+ conditions</li> <li>• Suggest that diagnostic overshadowing might account for deficits among these people</li> <li>• Communication problems (35%), mobility (11%) and behaviour (26%) barriers to accessing health care</li> </ul>
2837 Evenhuis, 1995	2	Quantitative	70 elderly people (44 women, 26 men) with mild, moderate or severe Id. Mean initial age 70.1 (range 60–92) One person with Down's, no profoundly Id people. Suggests represents mortality at younger age and probably representative of general Id population of this age in developed countries.	Older adult(60+)	mild, moderate, severe	<ul style="list-style-type: none"> <li>• Problems identifying needs with slow onset</li> <li>• Bilateral hearing loss in 33% of 60–70 year olds</li> <li>• Bilateral loss in 70% of 71+ year olds at first assessment</li> </ul>
3401 Wilson <i>et al.</i> , 1990	3	Quantitative	75 people drawn from 150 people who represented all the attendees at a Social Services Day Centre in Nottingham. The 75 were matched with the other 75 for age, race, level of ability, membership of special care group and presence or absence of Down's and profound sensory impairment – a 'balanced sample'. 10 refused consent so 65 took part. Most were in 20s and 30s. 25 female, 40 men. 18 had Down's, 27 cause unknown and 20 a 'collection of other diagnoses including perinatal problems and autism'.	Adult	All	<ul style="list-style-type: none"> <li>• 15/33 carers able to predict person with Id would 'fail' sight test</li> <li>• 13/27 able to predict the person would 'fail' a hearing test</li> <li>• 17 people with Id had one problem thought to be unmanaged</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
4060 Rustia <i>et al.</i> , 1984	4	Quantitative	US study of an elementary, junior high and senior high school. Number of children on school rolls 730+, 500+ and 1500+ respectively and in rural lower-middle to middle-middle SES district, suburban middle to lower-upper SES district and urban lower-middle to middle-middle district. Info collected from principals, teachers and parents of special need students and selected supportive personnel including nurses.	Primary-adolescent	Mild/ moderate	<ul style="list-style-type: none"> <li>School nurses referred for identified problems but did not share information gained with others</li> <li>Parents tended to share info with nurses but they did not consistently share this with teachers</li> <li>Suggest nurses need to transpose what they know about client care to school setting</li> <li>Could facilitate monitoring state of health</li> </ul>
4405 Munden <i>et al.</i> , 2002	3	Quantitative	Conducted in one urban health district in UK. Included most people working with people with Id with exception of inpatient nursing staff who were sample from long-stay, acute psychiatric and respite wards. 172 questionnaires sent by post or hand delivered to social workers (n=17, response rate 76%); psychologists (n=30, 30%); day-centre staff (n=16, 100%); staff from private care homes (n=10, 40%); hospital-run care homes (n=30, 16%); paramedic staff (n=20, 80%); Id psychiatrists (n=7, 85%); clinical assistants in psychiatry (n=2, 100%); general practitioners (n=20, 65%). GPs selected had patients with Id on register.	Older adult(60+)	All	<ul style="list-style-type: none"> <li>Difficulties recognising symptoms of depressive disorders by carers or professionals with lower levels of experience with mental health symptoms in people with Id</li> </ul>
4478 Goldsmith <i>et al.</i> , 2000	3	Quantitative	8/9 primary health care teams. Consent to access notes obtained from patients guardians/carers – 123 letters and info sheets sent, 117 (95%) granted permission. Records of 102 people included in final audit (one practice withdrew and so 15 could not be audited). Included 16 aged 16 and under (10 male), 86 aged 17 and over (48 male).	All	All	<ul style="list-style-type: none"> <li>Key problem for GPs ease of access to relevant information</li> <li>Found that relevant information for children not centrally recorded but held in disparate locations</li> <li>Information on breast and cervical screening suggest under-accessed</li> <li>Few recorded sight/hearing tests also suggest these services under-accessed</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
4510 Lennox <i>et al.</i> , 2000	2	Quantitative	Random sample of 912 GPs registered with the Health Insurance Commission database (Aus). Response rate to questionnaires 58%.	All	All	<ul style="list-style-type: none"> <li>Favourable attitudes towards health care and own role in it by GPs</li> <li>Data suggested inadequacies in dental care (14% facilitated)</li> <li>Health screening and medicine review facilitated by most GPs (47% and 73%)</li> <li>Suggest combined communication problems and time shortage lead to inadequate provision of preventive care</li> <li>Suggest results indicate GPs aware of inadequacies and intend to address them</li> </ul>
4621 Pearson <i>et al.</i> , 1998	3	Quantitative	62 women eligible for cervical screening and 12 women eligible for breast screening.	Adult	All	<ul style="list-style-type: none"> <li>24% women with Id had smear test vs 82% women in health district on average</li> <li>58% had breast screening within last 3 years compared to district average of 66%</li> </ul>
4642 Roy <i>et al.</i> , 1997	3	Quantitative	388 adults with a representative range of Id and social backgrounds identified from the local Learning Disability Register and GPs' lists. The PAS-ADD checklist was administered to the first 127 individuals with Id and their carers who agreed to participate. (141 were approached but 14 people declined to take part). Age range 19–89. 64% male and 46% female.	Adult	All	<ul style="list-style-type: none"> <li>Follow-through on referrals for psychiatric assessment not as successful as those for physical complaints</li> <li>Suggest symptoms seen as chronic by carers may not be seen as severe enough to warrant intervention by professionals</li> <li>Disputes of where people with Id should be referred to and reluctance of professions with high workload to respond to referrals from screening may contribute to delay</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
4702 Kon, 1997	3	Quantitative	74 people with Id resettled in an inner London health district in ordinary housing. 2–5 people in each house with support of 10–15 direct care staff. 54 assessed 5 years later.	Adult	All	<ul style="list-style-type: none"> <li>Access to specialist psychiatric services reported good or adequate by 78% care staff</li> <li>Almost all people with Id had visited GP in last year</li> <li>Over 5 years since resettlement an increasing use of hospital medical outpatient services</li> </ul>
4793 Gravestock <i>et al.</i> , 1995	3	Quantitative	All consultant psychiatrists, senior psychologists, senior nurses and managers in 15 health authority Id services and 16 corresponding local authority Id service managers. 55 questionnaires returned (response rate 72%). No statistically significant differences found between data from different professional and managerial groups nor between grouped data from London, Kent and Sussex districts, therefore data combined.	Adult	All	<ul style="list-style-type: none"> <li>Local clinical provision for people with Id described as part of specialist services rather than mainstream by 38% health care 'managers'</li> <li>Described as mainstream by 15%</li> <li>Id services viewed as more accessible than generic mental health services</li> <li>Availability described as good by 60% for Id services/31% generic services</li> </ul>
5317 Sham, 1996	3	Qualitative	6 families originating from Hong Kong but living in UK for 15–30 years (average 22 years). 5 mothers spoke no English and one a little. 3 fathers spoke no English, 2 at little and one good. Children with Id ages ranged from 11 to 20 years, 4 boys (all eldest) and 2 girls.	Adolescent (to 18)	All	<ul style="list-style-type: none"> <li>Access to services affected by cultural beliefs about causes of learning disabilities – punishment for parents</li> <li>Reluctance to accept permanent nature of the impairment</li> <li>Behaviour of the child with Id – avoiding 'losing face'</li> <li>Communication problems – language</li> <li>Interpreter problems – inadequate due to problems understanding information to be communicated</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
5342 Paxton <i>et al.</i> , 1998	3	Quantitative	People with Id over age 16 registered at 3 GP practices. 75 identified: 3 declined, 1 in hospital not included. 71 remaining: 32 women, 39 men, 13 living with family. 3 moved before feedback stage.	Adult	All	<ul style="list-style-type: none"> <li>Problems identifying mental health and challenging behaviour – greater tolerance in institutional settings</li> <li>Problems identifying epilepsy – paid carers little knowledge of epilepsy and person's seizure patterns</li> <li>People invited to GP epilepsy clinic did not make appointment</li> <li>Low number followed up recommendation to have sight check</li> <li>Concern over number of people with Id and health needs still failing to access necessary services</li> <li>Comment on important role of carer in this</li> </ul>
5357 Thornton, 1999	2	Qualitative	6 Community Teams in LD (CLDTs) comprising 39 professionals – CLDNs, social workers, occupational therapists, physiotherapists, dieticians, support workers, community consultant psychiatrists, an art therapist, placement manager and parent. 3 in location 1, 1 in location 2 and 2 in location 3. Also 11 Managers of small homes for people with Id, 6 location 1, three location 2 and 2 location 3. Sample purposive. Researcher had met some but majority unknown prior to research.	Adult	All	<ul style="list-style-type: none"> <li>Parents/carers can be barrier to health care</li> <li>Parents/carers can influence treatment decisions</li> <li>Highlighted importance of advocate, particularly in relation to communication problems</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
5646 Langan <i>et al.</i> , 1994	3	Quantitative	From authority's register drew random sample stratified by age and sex (n=149) from population of people with Id aged over 20 living in or originating from the health district (n=919). 56% in residential accommodation (greater than expected based on register info – 35% in residential accommodation). For each person selected control matched on age, sex and GP registration. Sample reduced to 127 due to people with Id being untraceable or deceased. Response rate 71% – data on 90 individuals. Study based on info from 76 carers of 81 individuals. Proportion of men to women 47:34. Differential response rate between paid (85%) and unpaid (54%) carers believed due to lack of personal contact with latter.	Adult	All	<ul style="list-style-type: none"> <li>42% given blood pressure checks in last 5 years compared to 69% of controls</li> <li>66% prescribed glasses but 33% of these had no sight test in last 3 years; only 6/81 cases carers thought testing necessary</li> <li>80% considered hearing tests not necessary</li> <li>Conclude opportunities for health promotion/screening/medicine review missed by GPs and not always picked up by carers</li> <li>2/3 carers with health promotion issues failed to bring it to attention of GP</li> <li>Some carers dissatisfied with medical reviews failed to act</li> </ul>
5748 Dodd, 1999	3	Quantitative	10 people with Id from three local residential homes, 5 men, 5 women aged 31–46 years all with verbal skills but variable degrees of comprehension and language use. 3 GPs providing primary health care to these individuals also participated.	Adult	Moderate	<ul style="list-style-type: none"> <li>Substantial improvement in knowledge of what to do when feeling ill, why and how to visit GP including role of receptionist, the need to provide symptom info and what happens in consultation. Majority retained this info at 6-month follow-up</li> <li>Increases in knowledge of body and processes for many – some reduction at 6-month follow-up</li> <li>Found those with highest knowledge/skill retention were those who had used communication aid pack during 6-month period</li> <li>Limited info on usefulness because sample small and occasion to use did not arise for several</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
5859 Hunt <i>et al.</i> , 2001	3	Quantitative	35 people with Id screened over 12-month period, 13 men 22 women, mean age 39, range 17–65. 32 lived with family, others in staffed group homes.	Adult	All	<ul style="list-style-type: none"> <li>Screening identified need in all 35 people and 91% referred to GP</li> <li>Communication barrier addressed by CLDN attendance at appointments with person with Id/carer. Nurse role: assist with communication; give concise accurate and relevant info from check; support GP with knowledge of conditions prevalent in person with Id</li> <li>Clients encouraged to access full range generic services</li> <li>Nurse able to signpost 'user-friendly' services</li> <li>Helped with preparation for service visits – pictures/symbols/photos/pre-visits</li> </ul>
6248 Jones <i>et al.</i> , 1997	2	Quantitative	19 practices approached, 6 agreed, 5 of which used handwritten medical records suitable for insertion of prompt (29 GPs). People with Id identified by practice staff on advice and with assistance of one of the researchers. Identified 11 people with Id from 5 practices (56 male, 55 female) randomly allocated to active and controlled groups. No significant difference in age, sex, marital status, cause or severity of Id, medical condition or specialist consultations. Mean age 41 years (18–72 range). 2 married, 2 divorced or separated, degree of Id estimated for those where enough info available: 28 mild Id, 39 severe (combination of moderate, severe, profound). 30 people had Downs syndrome. Mean consultation rate over previous 4.5 years 4.0 per yr (general population: 3 times for men, 5 times for women – 5 and 7 times for under 5s and over 75s). People identified randomly allocated to active and control groups.	Adult	All	<ul style="list-style-type: none"> <li>Care prompt notes had no significant effect on consultation patterns or health promotion issues</li> <li>15/30 people with Down's syndrome had never had thyroid function test</li> <li>'New' patients more likely to have received health promotion – compulsory under terms of GMS contract – this where health promotion was occurring</li> <li>Real problems identifying people with Id on register – no Id register input</li> <li>Conclude GPs unlikely to provide screening on opportunistic basis</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
6250 Lennox <i>et al.</i> , 1997	1	Quantitative	1000 randomly selected GPs from database: 88 excluded (retired, deceased, specialists, uncontactable) 526 responded (response rate 58%). 68% male; mean age 46.3 (SD 10.6) years, mean time in general practice 17.4 (SD 9.8) years; mean working hours 42 (SD 16.8). 65% some undergraduate training, 10% some postgraduate training in Id. Mean consultation time with person with Id: 19.5 minutes (range 5–60) compared to non-Id 13.5 (range 5–60). Average saw 9 people with Id in 6 months prior to survey, 60% 0–5, 27% 6–10. Average patients seen in one week 134.6; estimated proportion of patients with Id 0.7%. GPs appeared representative of GPs in Australia as whole.	All	All	<ul style="list-style-type: none"> <li>86% GPs felt responsible for medical care of adults with Id but only 70% felt responsible for children</li> <li>85% reported communication a barrier to provision</li> <li>80% reported communication with other health professionals a barrier</li> <li>89% difficulties obtaining a complete history</li> <li>76% uncertain of person with Id's baseline health and behaviour</li> <li>Lack of knowledge of conditions/ complaints in people with Id a barrier</li> <li>Time constraints also barrier to care</li> <li>Poor teamworking with other health providers</li> <li>Difficulties accessing system and services not geared to people with Id</li> <li>Poor continuity of care – carers seeking help from numerous doctors</li> <li>Examination difficulties</li> <li>Lack of back-up resources (specialists, clinics to consult or refer to)</li> <li>Issue of not seeking help for selves or not doing so early enough</li> </ul>
6271 Wells <i>et al.</i> , 1997	3	Quantitative	Representative sample of 120 adults with Id (from those caseloads where GP had agreed to participate) drawn from 334 identified from LD Register in Birmingham. 42% female, 58% male. Control group of wider population in same project area, 3846 females (51.5%) and 3623 males (48.5%).	Adult	All	<ul style="list-style-type: none"> <li>Significantly higher proportion of people with Id overweight, obese and morbidly obese</li> <li>No significant differences in diastolic blood pressure but 27/120 (22.5%) clinically hypertensive</li> <li>48% had done no moderately intense activity over the past 4 weeks</li> <li>Suggest supports evidence that people with Id at higher risk of developing CHD and stroke</li> </ul>

## ***From the Cradle to the Grave***

<b>ID &amp; details</b>	<b>Final Rating</b>	<b>Study design</b>	<b>Sample</b>	<b>Age group</b>	<b>Disability range</b>	<b>Access findings</b>
7785 Rawlinson, 2001	3	Quantitative	21 people with Id randomly selected from register of 96, revised to 94 due to moves and deaths and including 21 of original prospective participants selected. 33 living with family, 39 residential home, 12 warden scheme, 8 independent, 2 village community. 17 carers and 2 people with Id completed interviews (some carers on behalf of several people with Id). Participants: 10 men, 11 women, mean age 41.4 ( 20–79 years). Carers (17), immediate family 52%, home managers 18%, residential care staff 24% and warden 6%.	Adult	All	<ul style="list-style-type: none"> <li>• 81% registered with dentist</li> <li>• 38% informal care unregistered</li> <li>• 62% used CDS, 29% GDS as NHS patients</li> <li>• 71% generally satisfied needs being met</li> <li>• Dental health reported as having minor importance</li> <li>• Older people with few or no teeth assumed not to need dentist</li> <li>• Assumed person with Id would make them aware of pain/trouble – pain criteria for intervention</li> <li>• NHS dentists reported as hard to find</li> <li>• People with Id turned away as patients on grounds of medical condition or challenging behaviour</li> <li>• Suggest reason reduced availability due to privatisation</li> <li>• CDS barriers – infrequent surgeries, access awkward, inflexible or insufficient</li> <li>• Carers responsible for making and keeping appointments and accompanying person</li> <li>• Day centre withdrawal from this aspect of personal care produced confusion over responsibility sometimes leading to loss of registration due to non-attendance (possibly having to find new dentist if list full)</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
7849 Bristol & District CHC, 1998	4	Qualitative	46 self-selected participants shared their views with Project Not Group Members through structured discussions in their own recorded homes. Invitations issued in March 1998 via 'all known outlets' asking for people with Id and carers to relate their experiences. Invitations sent to voluntary groups, Recreational Activity Centres and 'known' individuals and carers. Press and radio also publicised to draw in non-users. 'We cannot quantify the percentage of respondents as Avon HA were unable to provide up-to-date numbers of people with Id living in family settings.' All areas served by Bristol & District CHC were equally represented.	Not recorded	Not recorded	<ul style="list-style-type: none"> <li>• Devaluation of knowledge and skills of carers</li> <li>• Access depending on assertiveness of carer</li> <li>• Transport crucial</li> <li>• Low expectations of health service by people with Id and carers</li> </ul>
7856 Singh, 1997	3	Quantitative	In each of 5 local authority areas covering England, Wales and N. Ireland: interviews with 25 GPs (5 in each area), face to face or over phone, 25 interviews face to face with people with Id and their carers. Questionnaires also sent to 1344 GPs identified by information sent from HA, and 1197 people with Id and 1218 carers identified through local disability organisations in each of 5 areas. No information on where areas were or how samples were selected – response rates 42% GPs, 69% people with Id, 45% carers.	Not recorded	Not recorded	<ul style="list-style-type: none"> <li>• 81% GPs felt health needs of people with Id less well met than rest of population</li> <li>• 64% said people with Id made fewer visits</li> <li>• Suggest as possible explanations: poor communication, low expectations, bad experiences and reluctance of carers</li> <li>• 42% GPs said they should not be the principal provider; 67% did not receive enough information on local services for people with Id</li> <li>• 87% unpaid and 86% paid carers said they monitored the health of the person they carer for – overall satisfaction was high</li> </ul>
7886 Nadarajah <i>et al.</i> , 1991	4	Quantitative	ATC used by 166 people with Id, 12 clients used the clinic. No info on age/gender level of disability. Care staff questionnaires sent to 21 people, 19 returned (response rate 90%).	Adult	All	<ul style="list-style-type: none"> <li>• 89% found clinic useful</li> <li>• Easier to refer patients who might not otherwise have come to medical attention</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
7920 Nightingale, 1997	1	Qualitative	The research was carried out in 3 phases and was all undertaken within the boundaries of the Norwich Health Authority as the case study area. Phase 1: the service-provider research population was made up of 1 GP, 1 practice manager or senior receptionist, and 1 practice nurse from each of 78 GP partnerships in Norwich Health District together with all 11 CLDN from the Region. 62 out of 78 participated. Phase 2: an analysis of written materials (health promotion leaflets on cervical smears and letters sent to patients about the service). Literature was collected during the practice interview phase from patient areas and by requesting it from practice personnel, the local Health Promotion Unit and contacting known providers. For copies of letters of invitation a sample of 20 practices was derived from the list of all general practices provided by FHSA. Every 4th name was selected regardless of whether they had participated in the interviews. Phase 3: a research population of women with Id which was convenient and amenable to approach was obtained via one of the CLDN who organised a women's group. Access and consent was negotiated by the community nurse facilitator. The group had been running for 2 years. 6 women were in the group but only 4 took part in the focus group.	Adult	All	<ul style="list-style-type: none"> <li>• A defensive model of cervical screening emerged to apparently protect vulnerable women, that actually served to protect the 'good intentions' of the service from unwanted patients</li> <li>• GP admitted finding women with Id difficult to provide a service for</li> <li>• Perceptions of Id reinforced staff behaviour via stereotyping by intellectual ability, 'mental age', sexuality, 'social value' and ability to cope/adapt</li> <li>• Risk assessment based on preconceptions about sexual activity</li> <li>• Difficulty undertaking tests led to preference to rely on carer/parent for communication</li> <li>• Psychological/emotional issues around cervical screening led in part to poor level of health education/promotion generally and wish to protect</li> <li>• Service designed around needs of practice not needs of people with Id or those with poor literacy</li> <li>• Concludes policy implemented on basis of beliefs of individual general practices rather than recognised body of knowledge</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
7921 Lyon, 1997	3	Quantitative	115 adults 18–64 who were drawn from the Special Needs Register in North Warwickshire. Basically the sample comprised all remaining from the 495 adults on the register once those who lived outside the area, or did not meet the age limits, or who it was established were already using the CDS, were removed. Of 115 invited to take part, 60 accepted, 32 declined and 23 did not respond. Of the 60 who took part, 29 lived in the family home, 21 in residential homes, 2 in nursing homes, 5 in own home and 2 in lodgings. 33 were males and 27 females. Mean age 40.5 (SD 14.1) and ages ranged from 19 to 63. 59 Caucasian, 1 Afro-Caribbean. Only 50 agreed to clinical examination.	Adult	Moderate	<ul style="list-style-type: none"> <li>• 42/60 currently registered with dentist</li> <li>• 65% attended in last year</li> <li>• 16% difficulty finding suitable practice</li> <li>• 71% never worried about dental visits</li> <li>• 54% of 50 people with Id examined needed further assessment and possible restorative care</li> <li>• 8% needed non-urgent referral and 6% urgent referral for oral lesions</li> <li>• 59% needed oral hygiene instruction and plaque removal</li> <li>• Despite identification of unmet needs majority had few concerns about oral health and most were content with present dental service and treatment</li> <li>• Suggest staff training to improve access</li> </ul>
7925 Gill, 2000	2	Quantitative	310 GPs registered with three HAs in the West Midlands – 51% response rate to postal survey (2 postings). 73% male mean age 46.8 yrs (SD 9.05, range 30–68) and 27% female mean age 44.8 (SD 9.52, range 28–68). States accurately reflects characteristics of total GP population in England/Wales (source RCGP, 1999).	All	All	<ul style="list-style-type: none"> <li>• GPs had positive attitudes, generally believed in accepting people with Id onto caseload but other scores suggested may be less willing to adapt their practice to meet individual needs</li> <li>• Younger GPs more positive than older ones and female GPs more positive than male GPs</li> <li>• Those with more frequent contact or larger caseloads of people with Id more positive (possibly personal choice)</li> <li>• Those practising longer (age controlled) also more positive</li> <li>• Notes GPs responding to survey may be more positive about providing care to people with Id – no info on non-responders</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
7943 Maternity Alliance, 1999	4	Qualitative	Self-selected by staff members – focus group, 'The Canterbury Partnership Group' comprising 9 people (LD Community Nurse, special needs midwife, Id nurse, 3 women with Id and no children who would like to have children, a couple with a daughter (mother has Id) and 1 mother with Id with a daughter). Two volunteers dropped out before group started.	Adult	Mild	<ul style="list-style-type: none"> <li>Only know if mother-to-be has Id through referral, otherwise may suspect only if woman states she cannot read</li> <li>Wall and ladder exercise to identify barriers and solutions</li> <li>Barriers: having to take tests; fear of mistakes; difficulty with questions; people thinking you were stupid to be pregnant; not having enough support; people thinking you were too young and couldn't cope</li> <li>Solutions: being given time to talk and plan ahead, knowing what you will be asked, being listened to and understood, having support, being able to see midwife at GP surgery, knowing people are happy for you</li> </ul>
8045 Ashman <i>et al.</i> , 1996	4	Quantitative	Drawn from a database of all known persons aged 55 and over with Id in Queensland and Western Australia. Database developed over 12 months by an intensive search of 5 general sources in each state i.e. government and non-government service providers, generic and specialist services in disability/ageing area, examination of existing directories and word of mouth. 514 people were identified, 446 agreed to participate (unclear whether people with Id or parent/carer). Results coded and compared with National Health Survey.	Older adult (60+)	All	<ul style="list-style-type: none"> <li>People prescribed glasses, hearing aids or dentures were not wearing them – staff found difficulties enforcing, also suggested glasses not necessary for people who did not read, write or appear interested in interacting with others</li> <li>Under-reporting of health conditions attributed to clients' poor communication and language skills</li> </ul>
8095 Beecham <i>et al.</i> , 2002	2	Quantitative	Registers of 6 special schools in 3 adjacent London boroughs provided the sampling frame for this study: 294 children aged 4–11 years. 139 (47%) of parents/carers agreed to participate. Severe Id was defined as Vineland Screener overall standard score of below 50; 114 children met the inclusion criteria for the study. Down's syndrome and cerebral palsy were the commonest diagnosis, but almost a third of children had no formal diagnosis. Only 8 children were under 5.	Primary school	Severe	<ul style="list-style-type: none"> <li>Weak association between severity of behaviour problems and contact with a clinical psychologist or psychiatrist. Children with 1 or 2 severe problems – none had seen clinical psychologist or psychiatrist.</li> <li>Suggests this result indicates under provision of mental health services</li> <li>Subjective reports support finding of high levels of unmet need in relation to behaviour problems</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8098 Hogg <i>et al.</i> , 2001	3	Qualitative	The literature overview was carried out by Professor James Hogg and does not claim to be systematic. Databases are named but little information on keywords and strategies used, grey literature was not accessed but hand searching of a large volume of papers on mortality was carried out. The learning from experience dataset was derived from placing a call for contributions in journals and conferences but this only led to a very small response. Owing to time constraints only 11 organisations were contacted and 16 individuals including 2 family members, 2 NHS managers, 7 supported housing staff, 1 general medical staff, 2 CLDN and 2 social workers. Information was not sought directly from people with Id.	All	All	<ul style="list-style-type: none"> <li>Concludes that there are problems with accepted practice around issues like access to screening</li> <li>Dearth of specific materials for people with Id on cancer</li> <li>Lack of knowledge information and adequate planning barriers to screening</li> </ul>
8120 DOH, 1999	3	Report, quantitative	24 local authority areas (postal survey) with follow-up fieldwork with local managers, practitioners, service users and carers in 10. 21 completed questionnaires and 7 visits were eventually obtained. The sample was constructed to ensure balanced representation across English regions and a variety of urban/rural experience.	All	All	<ul style="list-style-type: none"> <li>7/21 authorities: policies in place to ensure support available to access health services</li> <li>Problems with access and appropriateness of audiology (7/21), optometry (8/21), sexual health and family planning (9/21), screening and immunisation (9/21), chiropody (10/21)</li> <li>15/21 could access support for CLDT</li> <li>Significant problems developing appropriate and accessible health services for people with more complex or additional mental or physical health needs</li> <li>Underlying problems: 1 – unclear roles and responsibilities (9/21); 2 – health professionals who were 'not in tune with the way people with Id might experience health interventions'; 3 – fragmentation of services system meaning access varies between and within LA areas.</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8155 Kerr <i>et al.</i> , 1996	3	Quantitative	26 people with Id and 26 randomly selected controls matched on age/gender. Mean age 25.9 (range 3–75) 14 males (53.8%). Only 7 (26.9%) on Social Services register. 18 (69.2%) mild Id, 4 (15.4%) moderate Id, 4 (15.4%) severe Id.	All	All	<ul style="list-style-type: none"> <li>• People with Id have similar GP contacts as non-Id people but greater number of hospital outpatient and specialist clinic contacts</li> <li>• Significant differences in numbers screened for cervical cancer (20% vs 80%) and regular immunisation (40% vs 60%)</li> <li>• Rates urinalysis also significantly different (&lt;10% vs &gt;40%)</li> </ul>
8161 Cook <i>et al.</i> , 2000	3	Quantitative	289 general practice registrars employed across Australia randomly selected from central database of Australian RCGP.	All	All	<ul style="list-style-type: none"> <li>• Only 8% GP registrars (Aus) found it easy to take a history</li> <li>• 83% agreed that problems with history taking limited the quality of care provided</li> <li>• 18% felt had adequate training in Id</li> <li>• 85% agreed provision limited by poor communication with other health professionals</li> <li>• Concludes time restrictions, communication difficulties and uncertainties about baseline behaviour constrain continuity of relationships</li> <li>• Some felt specialists not GPs have the central role in management – especially in the care of children</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8172 Keywood <i>et al.</i> , 1999	3	Qualitative	2 groups of adults with Id (15 in 1 group, 11 in the other) who both attended day centres near to Liverpool University. One group (15) were known to the research team as they had contributed to the design of a DOH Guide for people with Id on staying healthy. The groups participated in 14 workshops (series of 7 on various aspects of health screening and day-to-day routine health care). Parents, relatives and carers of people who attended the day centres were asked to attend a meeting about health care decision making; poor response led to one small group workshop and 5 one-to-one interviews. Interviews with 11 (4 advocates and 7 with people with Id) who were not involved in the workshops derived from contacts made with people with Id in Sefton and Liverpool. Age of workshop participants ranged from 20s to 50s and involved people who lived independently and those whose opportunities for peer contact beyond the day service was limited. Workshop attendance in one centre remained constant; in the other it ranged from 4 to 11 people. The research used a participatory action research approach.	Adult	Not recorded	<ul style="list-style-type: none"> <li>Reliant on knowing others to facilitate access to health services – carers are gatekeepers</li> <li>Access affected by carer's own health issues/stress and coping issues and where dependent on one person</li> <li>Adults with Id broad understanding of importance of routine health checks</li> <li>Often asked to make decisions on basis of inadequate info</li> <li>Limited knowledge of own health needs limits freedom to make health care decisions</li> <li>Preparation for screening consistently valued – inadequate/implausible explanations alienate</li> <li>Dialogue between health professionals and carers obscures consideration of people with Ids capacity to give consent</li> </ul>
8175 Steele <i>et al.</i> , 2001	2	Mixed	The project was concerned with the ethnic minority population of Huddersfield. Families: 97 ethnic minority families were identified from the LEA SEN database for the South Kirklees area. 42% (38) took part. Children: from the 38 families permission was sought to interview the child, 22 who had children 7–19 years old agreed; of these the 18 who were ethnic minority children were interviewed between March and May 2000. 5 case studies were developed from the sample to illustrate issues. Staff: 3 focus groups were conducted with 23 professionals from charities, voluntary organisations and community leaders on issues facing ethnic minority children or children with Id, special schools and resourced provisions. 42 semi-structured interviews with staff from a range of services including teachers, therapists, doctors and social workers.	Adolescent (to 18)	All	<ul style="list-style-type: none"> <li>Communication problems as result of language differences the major barrier to access – 46% Asian families said had communication difficulties</li> <li>Health services inconsistent in providing interpreters and link workers when families needed them</li> <li>Solution – more information in own language, both leaflets and audio/video tapes</li> <li>Satisfaction with services related to listening, explaining and activating other support systems</li> <li>Children from ethnic minorities were found to receive fewer contacts for physio and occupational therapy</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8193 Freeney <i>et al.</i> , 1999	3	Mixed	Physical access audits of over 60 representative NHS premises, focus groups of disabled service users and a postal questionnaire of 500 disabled people. Working group chosen by NHS of representatives from key disability organisations advised and supported the project. No further information provided about how sample was selected or who was included.	Not recorded	Not recorded	<ul style="list-style-type: none"> <li>• Most often cited barrier inappropriate attitudes and behaviour of staff, including problems due to reported symptoms not being taken seriously</li> <li>• 21% noted major difficulty as confusing or poor signage</li> <li>• Point of entry difficulties – where to go reported by many people with Id</li> <li>• Way finding problematic particularly on large sites</li> <li>• Widespread perception that GPs and dentists may refuse to have a person with Id on list because they may take a disproportionate amount of time to treat</li> <li>• Access to mental health services major problem due to overshadowing – behaviour treated as symptom of Id</li> <li>• Major issue lack of information on health screening</li> </ul>
8216 Turner, 1996	3	Quantitative	337 questionnaires were mailed to statutory service providers of which 268 were returned (49% from Social Services departments, 38% from NHS trusts, 8% from members of joint teams, 5% from voluntary organisations, housing associations and resource centres). 71% of respondents were managers, 29% from front-line staff i.e. social workers, community nurses, dieticians, physiotherapists, occupational therapists, home leaders, psychiatrists and psychologists. No further information provided.	Not recorded	Not recorded	<ul style="list-style-type: none"> <li>• One-quarter of organisations had policy for health promotion – more common in specialist Id trusts and hospitals</li> <li>• 62% said provided health checks (more in NHS organisations)</li> <li>• Results suggest link between having a health lifestyle policy and activity in practice</li> <li>• Suggested these policies may be overlooked in generic provider organisations</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8217 Halliwell Surgery, 2002	3	Quantative	17 pld were identified from computer searches in the practice in 1996. 16 attended for health check. In 1998 patients were identified by reference to previous group, computer searches, clinicians personal knowledge and info. From LDHS 20 patients were identified in 1998. 16 attended for health check in 1998.	Adult	Not recorded	<ul style="list-style-type: none"> <li>81% saw GP in last year</li> <li>18% saw practice nurse for health check – 35% in last 3 years</li> <li>Smoking, BMI and blood pressure info recorded for 80%</li> <li>1998 preventive health care had improved, 85% health check in last year and 95% in last 3 years</li> <li>1998 similar level of unmet need identified as in 1996, 15/16 having 1–5 needs which had to be actioned by nurses or referred</li> </ul>
8228 Sense, 2001	3	Report Quantitative	Questionnaire to 2500 deaf-blind people and their families (not clear where drawn from) sent out in a variety of formats (large print, braille, moon, audiotape). 382 people responded (76 from parents/carers on behalf of the deaf-blind person and 306 from deaf-blind people). Response rate 15%.	Not recorded	Not recorded	<ul style="list-style-type: none"> <li>33% deaf-blind people felt GP did not understand their needs</li> <li>50% felt needs not fully understood as outpatient</li> <li>17.7% avoided visiting GP because communication too difficult; 5% knew if their practice had a text phone and 12% knew if their outpatient dept had textphone</li> <li>Recommends guidelines for health staff; ongoing maintenance and decoration to buildings to improve access; loop system to be fitted to reception and at least one consulting room; medical records to include info about specific need to ensure contacted in accessible ways; longer appointments and relevant staff alerted</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8240 Slevin, 1995	3	Quantitative	105 student nurses selected from a college of nursing in Northern Ireland divided into 3 groups: 1 – traditional students (n=33) who were nearing the end of their training and did not have experience in caring for people with Id during their education; 2 – Project 2000 students (n=35) who had been training for 9 months and had not yet been placed with people with Id. 3 – Project 2000 students who had been training for 14 months (n=37) who had recently completed a module with contact experience of people with Id.	All	All	<ul style="list-style-type: none"> <li>Student nurses who had contact with people with Id during training had more positive attitudes towards them than students who had not yet experienced working with people with Id</li> </ul>
8252 Pearson <i>et al.</i> , [no date]	3	Qualitative	Workshops/seminar series and interviews in 7 localities in England conducted in 1997. Over 260 people took part: 77 were people with Id, 74 were parents, more than 100 were managers and professionals in health, social care, education and voluntary sectors; 9 were linkworkers. One research project in Hackney looked specifically at improving the role of the Clinical Directorate for LD in transition. Agencies in Sefton also worked on this project, focusing on those aspects of health of young people with Id identified by PHC co-ordinator.	All	All	<ul style="list-style-type: none"> <li>Access at transition depends on supply relative to need and demand plus overcoming barriers around eligibility, transport and distance</li> <li>Major problems: assessment of needs; attitudes and skills of staff; continued access to speech and language therapy; continuity in referrals to specialist services throughout transition</li> <li>Change in dental and epilepsy services caused most distress</li> <li>Loss of health promotion and surveillance as a result of leaving school identified as concern</li> <li>Difficulties encountered with hospital care and mental health services at transition</li> <li>Disconnected from primary health care systems, lacked choice and opportunity all exacerbated by transition</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8255 McCarthy, 2002	3	Quantitative	Questionnaire survey of: 1 – all 314 GPS in one health district in South East England (23%), 73 responded; 2 – 156 staff in day services and 178 in residential services across England, although mostly in the South East. Response rates (24%) 38 and (16%) 28 respectively; acknowledged as low response rates so indicative rather than conclusive findings; 3 – relatives/carers of older women with Id; 37 were sent out but only 15 (40%) returned, all from mothers.	Adult	Not recorded	<ul style="list-style-type: none"> <li>42% provided specialist menopause service</li> <li>60% had never treated a woman with Id</li> <li>Among remaining 40% only seen 1 or 2 women with Id</li> <li>89% who had treated women with Id reported they were accompanied</li> <li>10% paid carers felt women with Id understood the menopause, 50% that women were anxious and confused</li> <li>Interviews with women themselves suggested that they knew little about the menopause and so did not feel there was anything to be confused about</li> <li>Concludes women need more support at physical than psychological level</li> </ul>
8273 Smiley <i>et al.</i> , 2002	2	Quantitative	All health boards, special health boards and NHS trusts in Scotland. Questionnaire was sent to chief executive of each of the identified 13 NHS PCTs which provided ID services and the general managers of the 2 health boards that fund services directly. The questionnaire was also sent to the lead clinician/clinical director of each service.	Not recorded	Not recorded	<ul style="list-style-type: none"> <li>Over 12 PCTs and 2 health boards found considerable diversity in provision which was not explained by geographical distances and responsibility for remote an rural communities</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8288 FPLD, 2002	2	Report, mixed	Evidence gathered over 1 year through: 1 – Committee of Inquiry meeting 6 times; 2 – forms in 2 versions (using symbols and the other drawings) were sent out to special schools and on the FPLD website, 98 were returned and analysed; 3 – family members; 4 – completed questionnaire for professionals, face-to-face interviews were held with 2 mothers from ethnic minority communities in London, in-depth phone interviews with 6 family members and through phone calls received from family members when an article on the enquiry was put in a magazine; 4 – professionals, some were invited and contributed orally to the enquiry, 700 questionnaires were mailed out and distributed via web. 134 responses were analysed, only 25 innovations were suggested. Note: none of innovations is reported substantially enough in report to assess individually; therefore this evaluation draws on main points made in findings and recommendations.	Adolescent (to 18)	Not recorded	<ul style="list-style-type: none"> <li>Physical health problems and illness risk factors for developing mental health problems – difficult to service in face of communication problems</li> <li>Suggests communication problems factor in development of mental illness for people with Id</li> <li>Suggests network of GPS schools, colleges, school nurses and social services to help overcome geographical and communication difficulties to work preventively against the development of mental health problems by recognising signs at an early stage</li> </ul>
8350 Donovan, 2002	2	Qualitative	Network or snowballing method (each informant nominates another person whom they consider to have relevant expertise) the underlying assumption being that insiders know who are the most knowledgeable nurses in the field. 8 nurses were interviewed in the care homes where they worked.	Not recorded	Severe	<ul style="list-style-type: none"> <li>Problems for unfamiliar carers in identifying need in people with severe or profound Id</li> <li>Carers may affect pain responses by being unresponsive to typical pain signals</li> <li>Carers' input in consultation influences diagnosis and may result in mis-diagnosis</li> <li>Suggests a trusting long-term caring relationship allows development of empathy, sympathy, interpretation of verbal and non-verbal signs and recognition of possible higher pain threshold important to high-quality care and access to appropriate services</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8352 Roy <i>et al.</i> , 1993	3	Quantitative	Retrospective postal questionnaire survey of all 24 Id consultant psychiatrists in the West Midlands Region. The postal survey was used to establish the number of referrals which had taken place from 1984 to 1989; every consultant who had received a request (10) was then interviewed personally to obtain information about the cases and the outcomes.	Adult	All	<ul style="list-style-type: none"> <li>• More women with Id referred to the consultant psychiatrists than men over the 5-year period (24:4) with regard to sterilization for fertility regulation</li> <li>• 14 able to give informed consent – 3 women capable of giving consent not asked and substituted by parents (2 subsequently wanted children)</li> <li>• Strong parental involvement evident supporting view that people with Id referred for sterilization have high parental involvement and that parents initiate requests, irrespective of abilities</li> <li>• No systematic procedure for comprehensive assessment evident so cannot be assumed treatment was in their best interest – efforts to inform person with Id limited</li> <li>• No assessment adequate to ensure the most appropriate course of action taken</li> <li>• 46% of those referred were sterilized</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8359 Kerr <i>et al.</i> , 2003	2	Quantitative	589 people with Id due for early placement in the community based at the Lennox Castle Hospital. The clinical work was carried out between 1995 and 1999. The hospital closed in April 2002.	Not recorded	All	<ul style="list-style-type: none"> <li>Problems identifying need with slow onset</li> <li>Nursing carers reported perfect vision for 49% when on assessment only 4 (&lt;1%) people had normal sight</li> <li>Carers considered 74% to have normal hearing when testing indicated 11% had normal hearing – 61% mild and 15% moderate or moderate/severe hearing loss</li> <li>Concludes there is need for carer training and periodic assessment to detect health problems – GP care alone not sufficient</li> </ul>
8377 Clarke, 2002	1	Qualitative	Users/carers: representative sample of 50 adults drawn from the Social Service Information System. 27 were finally interviewed (14 women, 16 men aged 21–87) (13 with carer, 13 without, 1 both ways). 3 carers were interviewed. A total of 35 interviews. Professional postal questionnaire: representative sample of 50 staff, 26 returned (52%). The survey also included a case analysis of 10 cases of emergency admission to inpatient care between January 2000 and September 2001 and a literature review.	Not recorded	Moderate	<ul style="list-style-type: none"> <li>Access reliant on long-term, reliable and understanding relationships</li> <li>Often recalled episodes of difficult or delayed access and lack of understanding where relying on care manager</li> <li>Carers also had responsibility of mediating information in hospital</li> <li>Primary problem for 66% requiring emergency admission related to additional need – mental health, age or antisocial behaviour; risk rather than therapeutic need determined admission</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8383 Speechley, 2002	3	Quantitative	The study was carried out in Manchester where statutory services for adults with a defined ld are provided by the Manchester LD Partnership (MLDP) which is an amalgamation of health and social services. Community Services are divided into 4 CLDT. The research was carried out in Area 1. Semi-structured questionnaires used to survey three groups: carers, referrers and optometrists. A non-probability, purposive sampling method was used to produce a sample frame for each group. Criteria were having profound and multiple learning disability (PMLD), person cared for must be 18 or over, 'main carer', live in Manchester in same circumstances as person they care for i.e. home or family placement. Carers: the 'open cases' list was used to identify PMLD cases. 9 met the criteria, all female. 6 were finally interviewed. Referrer group: 12 health and 18 Social Services staff who were employed by MLDP, based in area and had a role in direct contact with service users. Both qualified and unqualified staff were included. Optometrists: 14 optometrists located in the area, listed in local directory as providing services to the community. Other services providers eg. residential/network services and private day services who may highlight the need for a vision test were excluded owing to resource constraints and involvement with an earlier project.	Adult	Profound	<ul style="list-style-type: none"> <li>83% had not had vision test since leaving school (mean age 30)</li> <li>Barriers identified as physical, administrative and service issues, communication, attitudes and knowledge of staff and symptom identification</li> <li>Carers felt it within their role to identify problems and/or suggest vision tests</li> <li>3/5 optometrists felt their premises were accessible – though 2 had steps to the front door</li> <li>Identified need through changes in behaviour or physical change, sometimes 'tested' e.g. response to stimulus</li> <li>Enabled access through info gathering and sharing, appointment support, pre-visit skill practice, home visits or flexible appointment, transport and experience/creative service from specialist</li> <li>Optometrists identified physical barriers: administration, communication, attitudes and symptom identification</li> </ul>
8401 Rudkin <i>et al.</i> , 1999	3	Quantitative	12 clients (aged 18–40) with profound ld. No further information.	Adult	Profound	<ul style="list-style-type: none"> <li>Health care provided on ad hoc basis</li> <li>No client had all checks to adequate standard</li> <li>Noted lack of quality feedback to carers to assist in health improvement</li> <li>Recommends proactive system of full health monitoring to provide adequate health care</li> </ul>
ID &	Final	Study	Sample	Age	Disability	Access findings

## From the Cradle to the Grave

details	Rating	design		group	range	
8470 Cumella <i>et al.</i> , 2002	2	Mixed	2 practices took part. Practice A covered a wide rural area (list size 12,100) with former mental handicap hospital (many former residents now recorded live in community). Practice B was in an urban area (list size 2,400).	Not	All	<ul style="list-style-type: none"> <li>Health checks showed range of physical, neurological and psychiatric disorders and disabilities</li> <li>Also found sub-optimal diet, and no exercise of physical activity in between one quarter and one half of people checked</li> <li>Identified need in all but 1 patient</li> <li>Conclude referrals to specialists, GP or CLDT increase workload in short term but would reduce long-term impact on health service use and mortality</li> <li>Key areas of difficulty identified as making appointment, physical access and communication with primary health care team – consequences often no informed consent, misunderstood health education/information, negative experience</li> <li>Solutions – routine checks, address physical access, identify people with ld on register, routine use of double appointments, employ awareness strategies (dissemination) and communication training</li> </ul>
8478 Gilbert-McLeod <i>et al.</i> 2000	2	Quantitative	60 children: unknown number contacted by letter at day care, 74 responded. 5 excluded because did not return consent form, 9 excluded because day care centre had no children with developmental delay attending. Children aged between 2 and 6 years, 36 non-delayed, 24 delayed. No significant differences in demographic data between groups. All parents completing questionnaires primary or principal caregivers. Children with delay had range of disorders: autism 1, Down's syndrome 3, cerebral palsy 3, spina bifida 1, Apert's syndrome 1, expressive language disorder 8, general delays 7. Children severely impaired or physically disabled excluded. All families spoke English.	Pre-school	Mild/moderate	<ul style="list-style-type: none"> <li>Inadequate pain signalling</li> <li>Fewer help-seeking responses despite often closer proximity</li> <li>Increasing use of anger response with increasing age</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8498 Hutchinson, [no date, unpublished]	3	Qualitative	Case review in author's trust based in north-west town, 3 focus groups ranging in size from 3 to 8 people (17 people in all), facilitated by the researcher and a student nurse, lasting 1 –1.5 hours within day centres the participants were used to attending. A further 6 people from a larger random sample of cases open to 2 organisations who consented to be interviewed in relation to a recent event, i.e. adult experience. Interviews with health care professionals were snowballed from participants in focus groups; however, only 4 agreed to be interviewed: a RLDN, RGN, GP and consultant psychiatrist. They also agreed to case notes being accessed.	Adult	Moderate	<ul style="list-style-type: none"> <li>6/17 felt that they had consented to outcomes in relation to their health care but 11/17 felt they had just decided whether to agree with the decision of the health professional.</li> <li>Almost all wanted assistance to understand more about the intervention received – solution development of approaches to facilitate communication and understanding</li> <li>Health professionals expressed need for education/training in relation to issues of consent and assessment of capacity to consent</li> </ul>
8503 Carter <i>et al.</i> , 2002	3	Qualitative	List of target population compiled by staff working on a children's hospital ward, 21 families. From this sampling frame families were approached. 12 families (15 parents/carers) agreed to take part, children aged 5–16 years	Not recorded	Profound	<ul style="list-style-type: none"> <li>Parents felt child had 'learnt to live with pain'</li> <li>Depended on guesswork to identify pain, none taught to assess their child's pain</li> <li>Tended only to consult health professionals when own strategies for dealing with distress exhausted</li> <li>GPs offered concern and sympathy, pain team optimal pain management</li> <li>Feared resorting to hospital – associated with upsetting child and 'overshadowing'</li> </ul>

## From the Cradle to the Grave

ID & details	Final Rating	Study design	Sample	Age group	Disability range	Access findings
8505 Heslop <i>et al.</i> , 2002	4	Quantitative	Questionnaire posted to families of 370 contacts who were on Home Farm Trust Family Carer Database or had moved into one of their residential services. Families of a young person 13–25 living in England. 283 returned (76%). Majority were white (97%) and the skewing of the results as a consequence is acknowledged and review of evidence suggesting things would if anything be worse for ethnic minority families. 53% male, 47% female. 38% still at secondary school, remainder had left. Also in-depth follow-up interview with 27 parents and further 27 people with Id based on a purposive sample of those who were willing to be interviewed or who reported positive/negative experiences/outcomes.	Adolescent/ young adult	Not recorded	<ul style="list-style-type: none"> <li>52% of children with Id who had some transition planning reported no plans for health service transition – 18% well covered</li> <li>1/5 left school with no plan</li> </ul>
8521 Martin, 2003	2	Quantitative	A register was constructed by importing names from special needs registers including all patients with moderate, severe and profound Id that could be identified and those who were mild/moderate but with an identified syndrome e.g. Down's syndrome. All patients were over 18. A postal invitation was sent offering and appointment with the CLDT and then the GP immediately after. If no reply was received from letter a follow-up letter was made – 71 adults invited over 5 years; 16 attended each year, 12 on 4 occasions, 12 on 3 occasions. 14 additional people recruited over the study.	Adult	Severe	<ul style="list-style-type: none"> <li>Suggest rate of 1.6 interventions per patient per attendance for health check</li> <li>Difficulties assessing health gain or deterioration due to changes in care staff</li> <li>Suggest that for people with severe Id positive enabling of access may encourage familiarity, timely and appropriate access</li> <li>Referrals to psychiatrists, CLDT and others appeared to tail off after 2 years suggesting a 'front-loading' effect of long-standing problems not looked at for years</li> </ul>

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