

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

***Report for the National Co-ordinating Centre
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prepared by

Alison Alborz

Rosalind McNally

Angela Swallow

Caroline Glendinning

National Primary Care Research & Development Centre

University of Manchester

Address for correspondence

Alison Alborz

National Primary Care Research & Development Centre

University of Manchester

Manchester

M13 9PL

E-mail: alison.alborz@man.ac.uk

Telephone: 0161 275 3340

Fax: 0161 275 7600

Executive Summary

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.

'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.

Methods

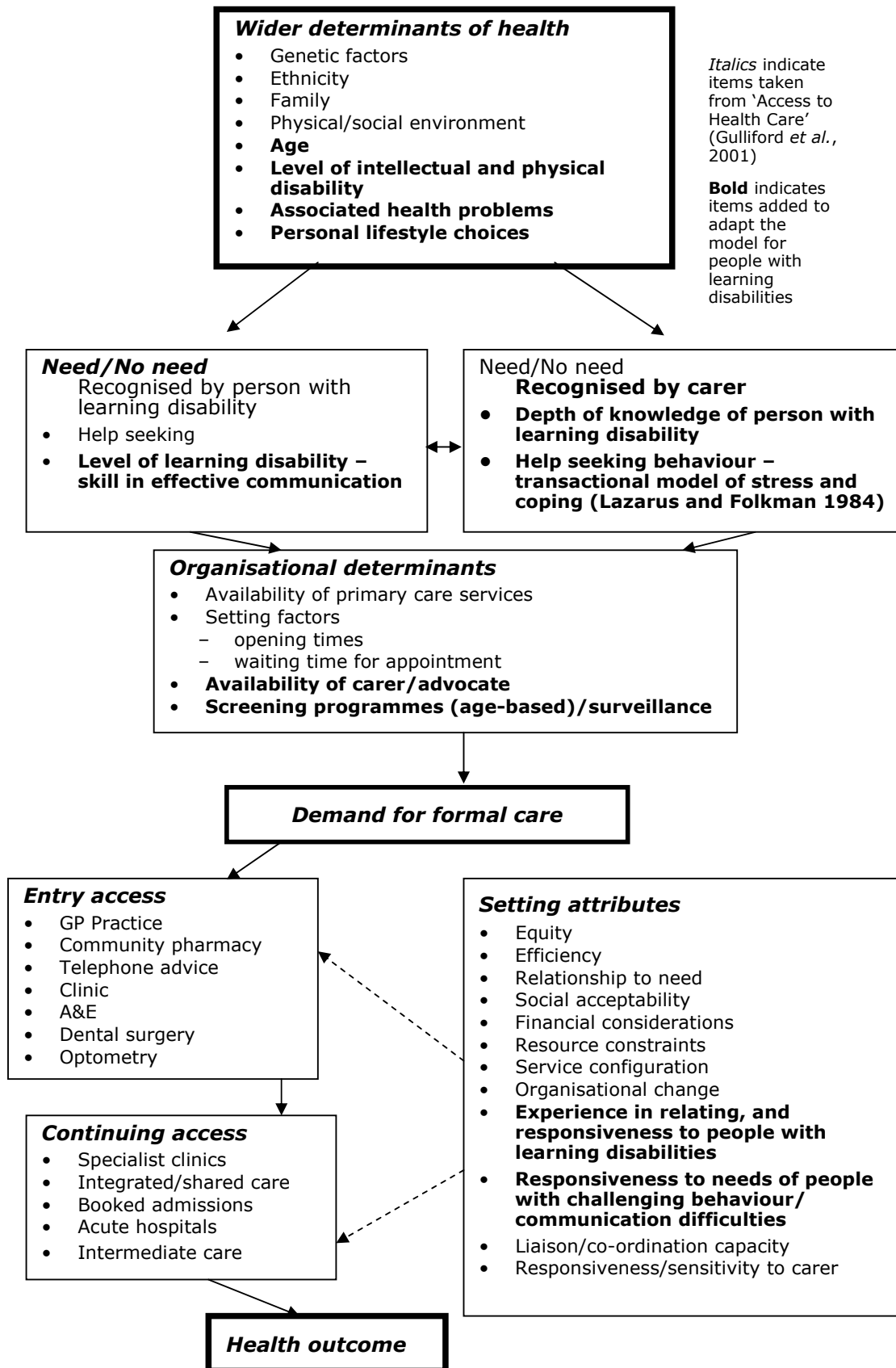
We drew on established methods for conducting literature reviews and adapted these to the diffuse and multidimensional topic of 'access'.

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



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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.

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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).

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

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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.

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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

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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.

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.

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

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- 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.

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Addendum

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The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk