ACCESS TO HEALTH CARE JULY 2004

BriefingPaper

Access to health care for people with learning disabilities

Key action points based on a literature review which examined the barriers to and ways to improve access to health care for people with learning disabilities:

- Identifying their own health needs is a big challenge for many people with learning disabilities; proactive strategies are required to help them access health care
- Barriers to appropriate and timely access to health services operate both outside and within health services
- People with learning disabilities say that negative or unhelpful attitudes of health care workers deter or stop them from seeking help
- Health care professionals need to develop better skills in communicating and working with people with learning disabilities and to adopt a proactive approach to identifying need
- 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
- Families and paid carers have an important role in helping many people with learning disabilities to access health care; however, carers have difficulty recognising mental health problems and noticing gradual changes in health
- Families with a child or adult with learning disabilities living at home may need encouragement to ensure that person gets regular dental check-ups
- GPs have a central role in ensuring access to the full range of services but need further information and support to help people with learning disabilities to access their services
- Specialist learning disability services are an important resource for facilitating adaptation of mainstream services to the needs of clients with learning disabilities
- Strategies such as health education and health checks for people with learning disabilities may promote timely access to health care
- New policies create opportunities to focus on improving access to health care for people with learning disabilities; at the same time, services need to ensure they implement requirements of existing policy initiatives that promote this goal

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NHS Service Delivery and Organisation R&D Programme

Access to *Care*

a reality for everyone

People with learning disabilities are more likely to have a wide range of physical and mental health problems than is usual for the general population. Moreover, these problems are likely to be long term. Some research has shown that carers and health care professionals find it difficult to recognise the health care needs of people with learning disabilities (Howells, 1986; Harries, 1991).

Two key aims of the NHS Plan are: to improve access to first-contact and continuing health care; and to reduce inequities in the use of health services by disadvantaged groups (DH, 2000). Policies for people with learning disabilities (DH, 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 developed, to improve access to and use of mainstream NHS services by patients with learning disabilities. (See also page 5.)

What difficulties and problems, then, do people with learning difficulties have in getting initial access to health services? And what is known about what works in improving initial entry and/or continuing access to the full range of mainstream health services by people with learning disabilities?

This paper summarises a review of research evidence and consultations on access to health care for people with learning disabilities across all groups/levels of disability. (For the model of 'access' used see About the Study, page 6.)

Practical *Findings*

Broader factors affecting health

The single study identified on this topic suggested that attempts to promote healthy lifestyle choices with this group 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.

Identifying health care needs

People with learning disabilities. The limited evidence on this topic showed that people with learning disabilities have difficulty identifying and/or communicating needs to carers and health professionals. Apprehensions about accessing services and perceived negative attitudes on the part of health care professionals may also deter more able people from seeking help.

Family and paid carers. Evidence suggests that long-term relationships with carers facilitate identification of need for people with more severe learning disabilities. However, carers appear less able to identify gradual changes in health (loss of hearing, eyesight) or spot mental health problems, and may be reluctant to seek help for problems they consider 'trivial', such as providing 'reading' glasses to someone who does not read.

Other professionals. The consultations but not the research (see *About the Study*, page 6) highlighted the roles of other professionals (e.g. school nurses, teachers, day care staff) in facilitating access and referral to health care, particularly for children with learning disabilities. The Special Educational Needs Review was also identified as a forum through which health needs among children with learning disabilities have been raised.

Organisation of health care

Shortages of provision. A shortage of provision was evident for some types of health services. However, this is likely to reflect deficits in general provision 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.

Language difficulties. A few studies 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 a lack of ability to translate medical terms impeded access to health care.

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

Accessing cervical and breast screening for women with learning disabilities. Research suggested that not all eligible women are invited for cervical screening or mammography and that inappropriate ways of informing those who are invited are often used. One highly rigorous study found that for more severely disabled women the assumptions of general practitioners and carers about the appropriateness of these preventive services resulted in failure to invite women for screening and in non-attendance respectively.

First contact with health care services

GP services. Research revealed general agreement among GPs that they are responsible for day-to-day health care of patients with learning disabilities. However, GP services are under-accessed by this group. Many GPs state that they lack information on learning disabilities and associated health problems. Communication difficulties, time constraints and difficulties in carrying out physical examinations were identified as affecting GPs' ability to provide an effective primary care service.

Dental health care. Parents may be reluctant to take their child to the dentist to put them through what they perceive will be distressing experiences. Children and adults with learning disabilities living with families appeared less likely to access dental services than either non-disabled siblings or adults living in formal residential care. Adults with learning disabilities living in informal family settings were found to have higher levels of tooth decay than those living in formal residential settings, to be less likely to have a dentist or regular check-ups, and only seek care when experiencing pain. Some people with learning disabilities using a number of services (day care and respite or residential care) had lost registration with their NHS dentist due to confusion over who was responsible for arranging appointments.

Accident and Emergency. Limited evidence suggested that some parents of children with severe learning disabilities may be reluctant to access A&E hospital services because these are perceived as upsetting for the child or because symptoms were likely to be dismissed as being part of the child's disability.

Ongoing access to health care services

Specialist outpatient clinics. Studies of users' perspectives suggested that negative attitudes towards people with learning disabilities among health care professionals can put them off using services. Studies also suggest that managing the transition from child to adult services depends on: adequate supply of services relative to need and demand; availability of funding; and agreement over respective responsibilities between child and adult services. Attitudes and skills of staff, as well as assessments of ongoing need, were often problematic. Difficulties were worse for children with complex health needs who used several specialist clinics, particularly when it came to maintaining access to epilepsy and mental health services as they moved into adulthood.

Mental health care. Problems were identified with accessibility of mainstream mental health provision, and some confusion among carers over the respective roles of learning disability and mental health services.

Innovations aimed at improving access to health care

Communication aids. Communication is a particularly important barrier to health care for people with learning disabilities. See 'Example'.

Example: Increasing health knowledge and communication skills of people with learning disabilities

A health education programme was provided for 10 people with learning disabilities using a communication tool to help them identify their health needs and communicate these to carers and professionals. Substantial improvement was reported in knowing: what to do when feeling ill; why/how to visit the GP; the receptionist's role; the need to provide symptom information; and what happens in a consultation. Most had retained this information at six-month follow-up.

Support to GPs. Only one study was identified: an initiative that involved attaching a prompt card to selected GPs' records that listed 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.

Health checks. Two studies found that although access to services was considered satisfactory, carers influenced whether referrals recommended by health care professionals during a health check were followed through. Referrals to mental health services failed to result in a specialist consultation, at least in the 12 months following the check.

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.

Overarching issues

Physical attributes of health premises. Little evidence was found to confirm that public service providers were removing physical barriers to access for people with disabilities as required by the Disability Discrimination Act 1995.

Information provision and access. Consultation with learning disability health services indicated that some individual practitioners and PCTs are making appropriate information available. However, no evaluations were found of the effectiveness of any materials developed. Consultation with parents suggested that there were problems with health professionals not sharing information for reasons of confidentiality which led to duplication of medical investigations. The proposed introduction of a single electronic health record may help to address this problem.

Staffing. A number of barriers to access were identified relating to health care provision. These include: professionals' attitudes, knowledge and interpersonal skills, and fragmentation of care between different health care professionals. However, there is no evidence on these barriers from a workforce perspective, or how they might be overcome.

Health costs. High levels of need identified may reflect a 'health backlog' due to difficulties in identifying need and seeking health advice in the past. So while improved access to services is likely to result initially in high demand, and thereby act as a drain on financial resources, it is unlikely that it would remain at this level in the longer term.

Further *Research*

agendas for action

Findings from the consultations confirmed that access issues are of considerable importance for people with learning disabilities. The review also identified several gaps and weaknesses in the literature which could be addressed by further research. Taken together, these findings can be used to build up agendas for further research and/or action as follows.

Research/action to *improve identification of health need* among people with learning disabilities

- Investigate health concepts among people with different levels of learning disability
- Investigate help-seeking decision making by people with learning disabilities and their carers
- Develop health education and communication aids to facilitate health need identification and communication by people with learning disabilities and their carers
- 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/action focused on changes in the *organisation of health care*

- 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
- Ensure the information needs of people with learning disabilities and their carers are met, including information about services available, and clear signs and notices in health care settings
- Assess 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
- Evaluate the success of health checks in providing evidence for health action planning and supporting access to mainstream health services

Research/action focused on *health care delivery* to ensure people with learning disabilities 'gain access' to services

- Develop effective and acceptable ways of providing information on learning disabilities, associated health conditions and specialist services to health professionals
- Develop appropriate undergraduate and in-service training on working with people with learning disabilities to improve professionals' expertise
- Investigate the role of learning disability health professionals in supporting mainstream colleagues in providing accessible health care to people with learning disabilities

Research/action that focuses on *ways to support* people with severe and profound learning disabilities to access appropriate mainstream health care services and to develop *complementary but not 'segregated' schemes* where standard mainstream provision cannot be accessed

Research/action to improve 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/action to *improve access* to

- dentists, opticians and audiologists
- A&E and ongoing health care services

About the *Study*

Background. Between June 2002 and May 2003 the National Primary Care Research & Development Centre (NPCRDC), University of Manchester, was commissioned by the SDO Programme to undertake a literature review of access to health care for people with learning disabilities across the lifespan (Alison Alborz, Rosalind McNally, Angela Swallow and Caroline Glendinning, 'From Cradle to the Grave', December 2003).

Conceptual framework. The literature used a multi-faceted model set out in 'Access to Health Care' (Gulliford *et al.*, 2001). This illustrates the diverse influences on entry and continuing access to health care and proposes a model to demonstrate the interactions of these factors, based on the needs of the general population. This model was modified by the Review to take into account the health problems and care needs of people with learning disabilities, particularly the additional features of their help-seeking behaviour.

Methods. These were adapted from the best-practice methods developed by the Centre for Reviews & Dissemination, University of York (www.york.ac.uk/inst/crd/). The Review examined and summarised evidence from published and unpublished literature (both UK and international) between 1980 and 2003 about access to health care for people with learning disabilities.

Field work. A series of consultations took place concurrently with groups of people with learning disabilities (n=11) and carers (n=14), and members of organisations (n=13) representing the interests of people with learning disabilities. Groups discussed access to healthcare and issues raised guided the scope and direction of the literature search. In addition, other researchers in the field and learning disability professionals (n=300) were contacted to identify literature unlikely to be indexed in electronic databases.

Assessment criteria. The literature used a range of methodologies and so different quality assessment criteria were employed. Assessment took into account the appropriateness of the research design, data sources, research instruments/data collection procedures used, and, importantly, whether emergent findings connected with existing bodies of theoretical knowledge or generated new understanding and demonstrated transferability. Qualitative research was also examined for validity and adequacy of explanation. The review also considered whether confounding (i.e. a relationship between 2 or more variables which prevents their effects from being evaluated separately) may offer an alternative explanation to findings of quantitative studies.

Results. Eighty-two studies were fully evaluated, including 15 qualitative, 62 quantitative and 5 mixed-method studies.

References and further reading

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Harries, D. 1991. *A Sense of Worth: A report on services for people with learning disabilities and sensory impairments*. London: Committee on the Multi-Handicapped Blind

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Further *Information*

The full report, this briefing paper and details of current SDO research in the field can be downloaded at: www.sdo.lshtm.ac.uk/access.htm

An 'easy read' summary and accompanying audio CD, called *Getting Healthcare*, will be available (Autumn, 2004). To obtain a copy contact Alison Alborz at the NPCRDC: Email: alison.alborz@man.ac.uk Tel: 0161 275 3340

This briefing covers the important issue of healthcare for people with learning disabilities. It highlights the practical aspects to be addressed if people are to be able to access health services and makes recommendations for action and further research including the need for better information and training. The paper should be of particular interest to members of Learning Disability Partnership Board subgroups for Health.

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About the SDO Programme

The SDO R&D Programme is a national research programme managed by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) under contract from the Department of Health's R&D Division.

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Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

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