



Access to health care for disabled people: a systematic review

Jeremy C Gibson

Department of Rehabilitation Medicine, Royal Derby Hospital, UK; Jessop Medical Practice, UK

Rory J O'Connor MD FRCP

Academic Department of Rehabilitation Medicine, Leeds Institute of Molecular Medicine, University of Leeds, UK

Abstract

The objective of this paper was to systematically review published studies to determine if disability limits access to health care and to attempt to identify what body functions, structures and activities and participation, as well as contextual factors (environmental and personal factors), interact with the health condition to limit this access. The AMED, CINAHL, EMBASE, Medline and psychINFO databases were searched for original study articles in English, dating from 1974 to 2008. Review articles and expert opinion were excluded. Each study had two independent reviews by either a general practitioner or specialist in rehabilitation medicine. Each study was critically appraised according to the *National Service Framework for Long-term Conditions* (Department of Health, 2005a) methodology and recorded on standardised data extraction sheets. Studies of poor quality were excluded. Sixty studies were included. No randomised controlled trials were identified. Studies broadly fell into the following three main groups: database studies (n=27), quantitative surveys (n=20) and qualitative interviews (n=13). Disabled people are restricted in accessing health care and report less satisfaction with their medical care. Many of the identified studies were from the United States (US) and based on subjective reporting. More objective evidence is needed, especially in the UK, to clarify the true level of access to health care in people with disabilities. The complex, interdependent factors in providing health care to disabled people require complex solutions.

Key words

Health care; disability; access; limitations.

Introduction

Disability affects all cultures and age groups (Groce, 1999). In the United States (US), up to 18% of children have special healthcare needs (Bent *et al*, 2002) and adult self-reported

disability is approximately 20% (Diab & Johnston, 2004; Iezzoni *et al*, 2001). As life expectancy increases for a number of disabling conditions (Baird & Sadovnick, 1988; Hutton *et al*, 1994) and survival rates for previously fatal

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conditions improve, the number of disabled people living in the community is set to rise.

Disabled people may not receive the same quality of health care as the general population, nor benefit as much from routine screening programmes, with severity of disability reducing participation in health promotion (Diab & Johnston, 2004). We systematically reviewed published studies to determine if disability limits access to health care, including preventative services, routine screening and dental services, and, if possible, identify what impairments, activity limitations and participation restrictions (disabilities), as well as contextual factors (environmental and personal factors), interact with the health condition to limit this access. Although our review focuses on healthcare issues, we feel that limited access to health care may well have a detrimental effect on the use of social services by disabled people.

Methods

We performed a literature search for original studies using a combination of key words (**Box 1**) across a range of databases (**Figure 1**, opposite). Titles obtained from initial searches were independently reviewed. After independently selecting titles for inclusion, the authors met to determine which articles were to have an abstract review. A further meeting was held to determine inclusion for full article review. We also included relevant papers from our personal archives for full article review.

We excluded review articles, expert opinion, consensus statements, letters, case reports, book reviews, and articles based on third party opinions and those focusing solely on levels of US healthcare insurance. Because of the nature of this review, and the types of articles identified, the quality of each article was assessed using the rating method from the UK *National Service Framework for Long-term Conditions* (Department of Health, 2005b). This approach has face validity and has been used in other rehabilitation systematic reviews (Sansam *et al*, 2009) and in the formulation of national guidelines in the UK (Royal College of Physicians *et al*, 2008).

Articles were scored out of 10 with up to two points awarded for each of five items:

1. Are the research question/aims and design clearly stated?
2. Is the research design appropriate for the aims and objectives of the research?
3. Are the methods clearly described?
4. Is the data adequate to support the authors' interpretations/conclusions?
5. Are the results generalisable?

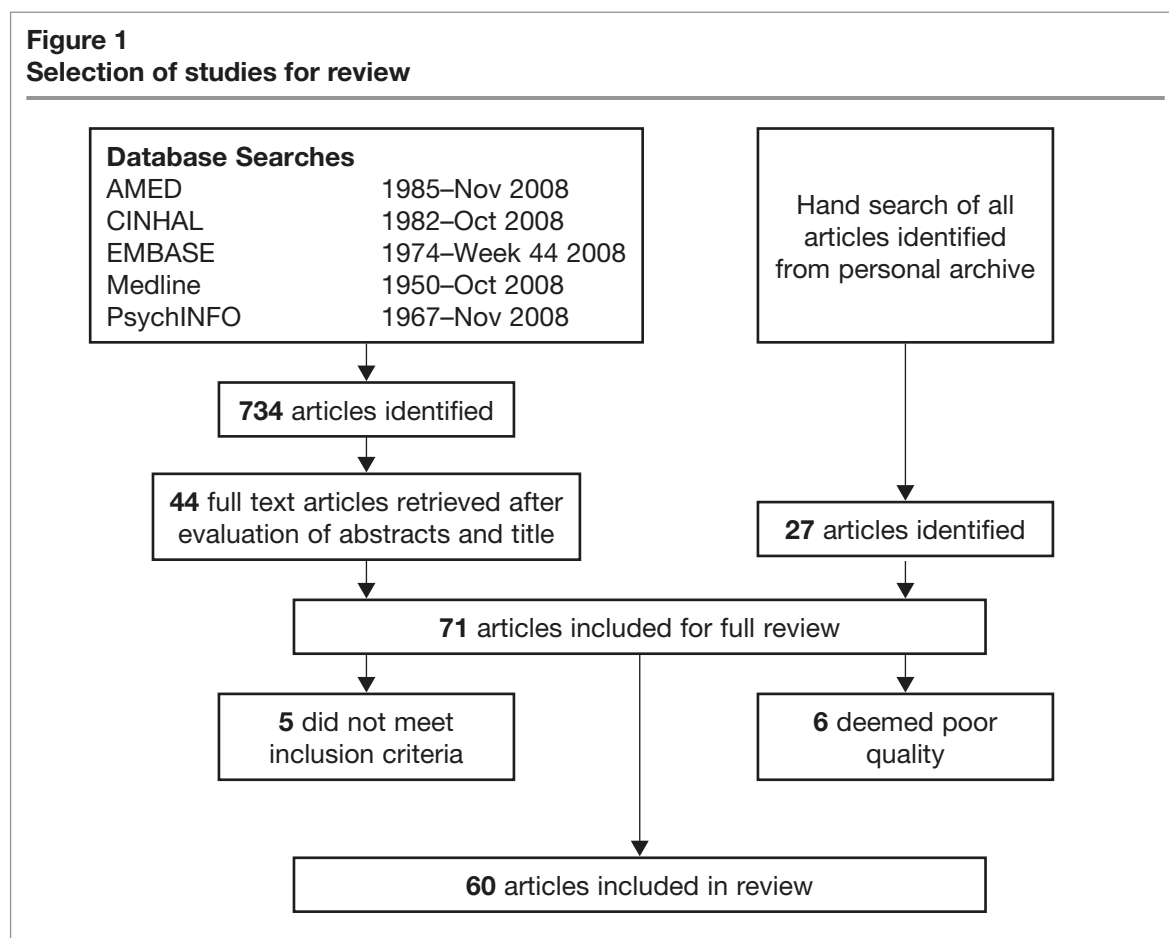
At a final meeting, all papers were discussed and the quality score for each paper was agreed. All papers scoring less than four were considered of poor quality and excluded, as per the methods of the *National Service Framework for Long-term Conditions* (Department of Health, 2005a). After further discussion, more papers were excluded

Box 1

Key words and phrases used in database search

1. Impairment
2. Body function
3. Activity limitation
4. Disability
5. Participation restriction
6. Handicap
7. Environment
8. Personal
9. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8
10. Medical
11. Preventative
12. Healthcare
13. Screening
14. 10 OR 11 OR 12 OR 13
15. Mammography
16. Papanicolaou
17. Smears
18. Blood pressure
19. Dental
20. Immunisation
21. Smoking cessation
22. 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21
23. Access
24. 9 OR 14 OR 22
25. 23 AND 24

Figure 1
Selection of studies for review



when both authors agreed that they did not address the aim of the study. Both authors agreed the final list of papers included in the results section.

We used the *International Classification of Functioning, Disability and Health* (ICF) (World Health Organization, 2001) to present the data identified from these studies, although the health condition was the largest category (**Figure 2**, overleaf). The ICF allows integration of the biomedical and social models of functioning and disability into a single biopsychosocial classification system (Ustun *et al*, 2003). Functioning is divided into the components of body functions and structures and activities and participation, which interact with contextual factors (environmental and personal factors) and the health condition to determine an individual's health experience. We have attempted to summarise the data according to the ICF model.

Results

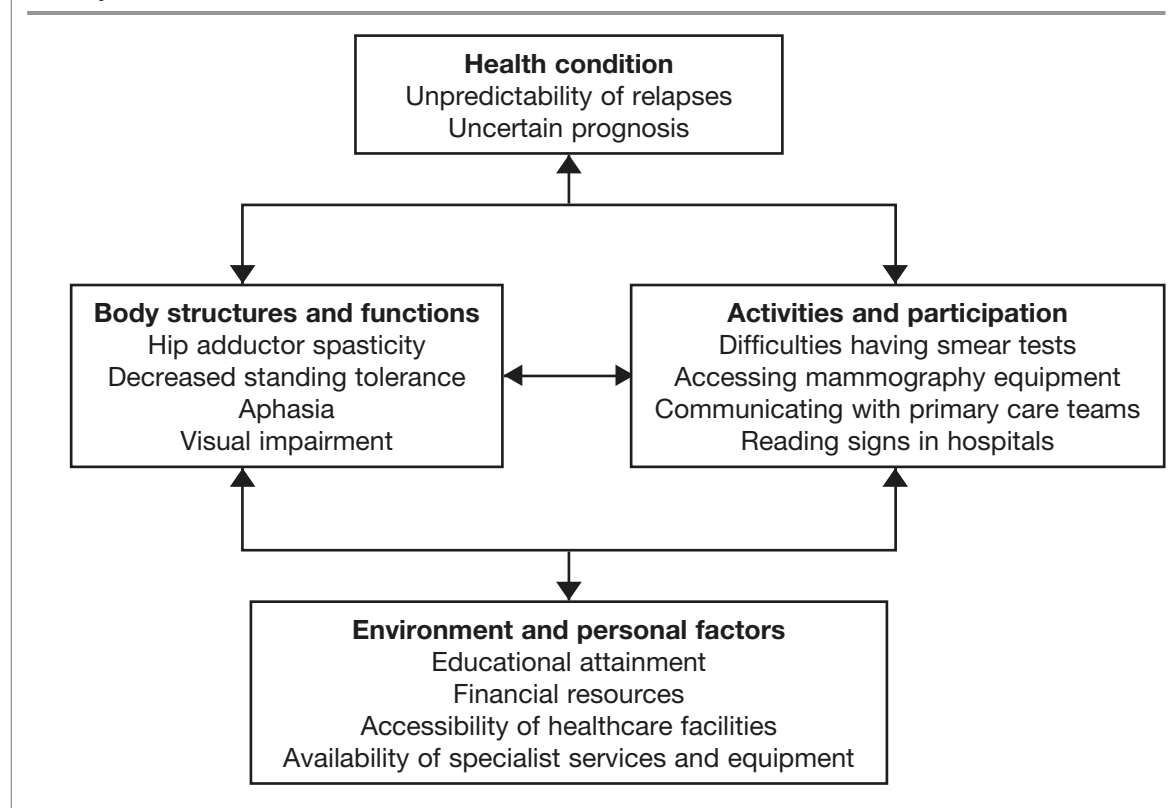
Initially, 734 articles were obtained from all five bibliographic databases (**Figure 1**); after abstract and title evaluation, 44 were retained, as well as 27 articles identified from our personal archive. In total, 71 articles were included for full review. At this stage, five were identified as not answering our research question and excluded. Six were excluded because of low quality, leaving a total of 60 articles of medium or high quality.

The included articles broadly fell into the following three main groups: database studies (27), quantitative surveys (20) and qualitative interviews (13). No randomised controlled trials were identified.

Health condition

For adults living with childhood-onset conditions, such as cerebral palsy and spina bifida, many report that condition-specific

Figure 2
Examples of barriers to health care in the ICF framework



medical follow-up ceased once they reached 18 years of age, the transition from childhood to adulthood representing a significant landmark in deteriorating access to medical services (Lotstein *et al*, 2008). However, the perception of limited access to health care is not restricted to those moving into adulthood with childhood-onset conditions. Even older disabled adults report experiencing a disparity in access to healthcare services in comparison to non-disabled older adults (Rummery *et al*, 1999; Smith, 2008a).

Multiple sclerosis and motor neurone disease

A Northern Irish retrospective case series suggested that people with multiple sclerosis may be less likely to receive some preventive healthcare and screening services, especially those who are more disabled. Rates of screening for hypertension appeared to reduce in people with multiple sclerosis (MS) as physical disability increased (MacLurg *et al*,

2004). A large US-based questionnaire survey stated that screening rates for cervical smear tests and mammography appear to be lower in non-ambulatory women with MS, than those who are ambulatory (Cheng *et al*, 2001). People with multiple sclerosis and motor neurone disease in Ireland have been reported to have limited access to appropriate hospital and community-based services with much of their equipment being provided by charities (Hardiman *et al*, 2003). In Australia, people with multiple sclerosis report difficulties accessing rehabilitation (Khan *et al*, 2006).

Learning disability

People with learning disability may be less likely to receive appropriate investigations and treatment compared to the general population (Disability Rights Commission, 2006). One reason for this suboptimal care may be diagnostic overshadowing (Ali & Hassiotis, 2008). Although people with Down's syndrome commonly develop

hypothyroidism, coeliac disease and obesity, surveillance of these sequelae is inconsistent. In a retrospective case series, Henderson and colleagues (2007) reported that up to one-third of adults with Down's syndrome did not have a medical assessment in the previous three years.

Gradual hearing and visual loss can go undetected in intellectually disabled people living in residential care, suggesting that regular screening for these impairments would be appropriate (Kerr *et al*, 2003). People with learning disability in Sweden have low levels of access to therapy services (Gustavson *et al*, 2005) Young adults with cerebral palsy in Singapore reported significantly lower access to rehabilitation medicine specialists and therapists, fewer contacts with general practitioners, and increased social isolation after leaving special schools (Ng *et al*, 2003).

Mental health conditions

A mental health condition increases the likelihood of being unable to obtain necessary medical care (Druss & Rosenheck, 1998). People with psychiatric conditions are less likely to have a primary care physician and more likely to perceive barriers to accessing medical services (Bradford *et al*, 2008).

Spinal cord injury, acquired brain injury, stroke and arthritis

People with disabling neurological conditions (spinal cord injury, acquired brain injury, stroke and arthritis) report greater barriers to services than the general disabled population (Shigaki *et al*, 2002) only one-half receiving rehabilitation services (Beatty *et al*, 2003). A postal survey of adults with either rheumatoid or osteoarthritis found that 39% reported not receiving rehabilitation services (Hagglund *et al*, 2005).

Impairments and activity limitations

Activity limitations resulting from underlying impairments can make receiving medical care more difficult.

Mobility

A large US national database study found that people with mobility impairments are more likely to receive routine immunisations for pneumonia and influenza, but less likely to receive other, incident-specific immunisations such as tetanus (Iezzoni *et al*, 2000). This may mask the tendency for more physically disabled people to fail to receive these immunisations (Diab & Johnston, 2004). Hip adductor spasticity in people with multiple sclerosis limits hip abduction, making cervical smears more difficult. Women with severe mobility impairments appear less likely to receive regular cervical smears, mammograms and smoking queries than those without mobility impairments (Iezzoni *et al*, 2000; 2001; Wei *et al*, 2006).

Cognition and communication

Working-age women with cognitive impairments have lower rates of cervical cancer and breast cancer screening than non-disabled women (Parish & Saville, 2006). Communication limitations experienced due to intellectual impairments or following a stroke can frustrate patients, families and primary care staff (Murphy, 2006).

Contextual factors

The ICF expands our horizon in viewing the impact of disabling conditions by including contextual factors that compound the problems experienced by individuals. The shortfall between patients' needs and the healthcare resources available creates tensions for frontline staff, and the way that these are managed impacts on disabled peoples' access to health care. Disabled people find considerable difficulty negotiating their way past barriers erected by administrators and frontline practitioners to control the demand for services (Rummery *et al*, 1999).

It is not surprising, therefore, to find that disabled people report lower levels of satisfaction with their medical care than non-disabled people (Fouts *et al*, 2000; Rohrer *et al*, 2008) especially those in the US who are uninsured (Gulley & Altman, 2008), with

the most severely disabled appearing most dissatisfied (Patrick *et al*, 1983).

Patient costs

Several studies report the cost of care and medication being an issue for disabled people receiving or being satisfied with medical services (Gulley & Altman, 2008; Hagglund *et al*, 2005; Iezzoni *et al*, 2002; Jha *et al*, 2002; Neri & Kroll, 2003; Smith, 2008a).

Children with special healthcare needs are defined as those children who have, or are at increased risk of, a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that generally required by children (McPherson *et al*, 1998). Families who have children with special healthcare needs report increased financial burden of health care (Houtrow *et al*, 2008).

A mental health condition increases the likelihood of delaying seeking health care because of the cost (Druss & Rosenheck, 1998). Women in the US with functional limitations report finding it harder to obtain general medical care, dental care, prescription medicine or eye glasses because of financial problems or limits placed on healthcare insurance. They are more likely to delay seeking, or not seek medical care because of the cost (Chevarley *et al*, 2006; Smith, 2008b).

Reimbursement for medical services

Part of the problem of availability of services for disabled people lies with doctors' reimbursement arrangements, such as the quality and outcomes framework (QOF) in the UK general medical services contract. Incentive-based reimbursement may mean that general practice consultations now reflect a wider population-based agenda to the potential detriment of patient-centred care (Mangin & Toop, 2007). Exception reporting in QOF may discriminate against younger or more socio-economically deprived people following stroke who are more likely to be recorded as having refused to attend for review or not replying to letters

asking for attendance at primary care clinics (Simpson *et al*, 2007).

In a survey by Al Agili and colleagues (2004) 35% of parents with children who have special healthcare needs reported problems finding dentists willing to treat their children. The reasons included: medical aid insurance not being accepted by some healthcare providers; poor oral health of children with special healthcare needs; and shortage of specialist dentists.

Transportation

Older disabled adults and disabled residents in rural areas experience difficulties in accessing appropriate transport (Smith, 2008a; Iezzoni *et al*, 2006). African-American disabled women also have problems with affordable accessible transport, affecting their access to motherhood and reproductive health services (Smith *et al*, 2004). Distance to specialist units may influence individuals' choices for certain aspects of health care (Iezzoni *et al*, 2006).

Physical barriers

Disabled patients find it difficult to assess physicians' offices and, once inside, experience other barriers such as fixed height examination couches that impede transfers (Mele *et al*, 2005; Smeltzer *et al*, 2007). Disabled people can experience barriers accessing dental surgeries and many wheelchair users require a hoist to enable them to sit on a standard dentist's chair (Baird *et al*, 2007). Women with physical activity limitations can find standing difficult during a mammogram (Smeltzer *et al*, 2007).

Attitudes

Clinicians' attitudes can affect disabled people's understanding of the importance of health screening (Steinberg *et al*, 2002). While specialists may lack knowledge about general health issues, general practitioners may lack knowledge about outcomes in specific disabling conditions (Iezzoni *et al*, 2002; Smeltzer *et al*, 2007). Some disabled women report finding healthcare providers patronising, lacking knowledge about

disabled people, and that clinicians may not take the time to explain health issues fully with them (Smeltzer *et al*, 2007; Smith *et al*, 2004). Disabled patients are more at risk of substance abuse, but half as likely to use substance abuse services as others (Krahn *et al*, 2007); one of the reported barriers is stigmatisation by clinicians and agency personnel (Krahn *et al*, 2006). People with mental health conditions express fear of attending medical appointments alone. There is a sense of frustration that their physical health concerns are often not taken seriously, that treating doctors are impersonal towards them and they worry that they may not be listened to or taken seriously (McCabe & Leas, 2008).

Personal factors

Recognition of an individual's personal issues is an important part of delivering health care for all conditions. In the ICF framework (World Health Organization, 2001), personal factors include an individual's practical and financial resources, which overlap with the cost of services as mentioned previously. People with long-term neurological conditions are often poorer than non-disabled people (Hardiman *et al*, 2003).

Personal factors that affect access to health care for children with special healthcare needs include: having a carer who experiences depression (Gaskin & Mitchell, 2005; Inkelas *et al*, 2007); those whose parents are in poor health (Krauss *et al*, 2003); and those who are black and come from less educated and poorer families (Inkelas *et al*, 2005; Inkelas *et al*, 2007; Kane *et al*, 2008; Kane *et al*, 2005; Lewis *et al*, 2005; Mayer *et al*, 2004; Newacheck *et al*, 2000; Porterfield & McBride, 2007; Stein & Silver, 2005; Weller *et al*, 2003).

People under 65 years of age who are socio-economically disadvantaged and have had a stroke report less access to health care, including appropriate secondary prevention, than older people who have had a stroke, and are less likely to attend for review in primary care (Levine *et al*, 2007; Simpson *et al*, 2007).

Discussion

The ICF provides a framework with which to categorise and discuss the barriers that disabled people experience. The quality rating method we chose has been used effectively and is methodologically sound (Sansam *et al*, 2009; Department of Health, 2005b; Turner-Stokes *et al*, 2007). This approach was used because of the wide variety of publications identified in our literature search, ranging from papers derived from large US national databases containing tens of thousands of people, to small qualitative interview-based studies. No randomised controlled trial designed to improve disabled people's access to health care was identified.

We appreciate that a number of inevitable weaknesses exist in a review in this area. Most of the studies centred on subjective opinions rather than objective assessments. By including studies of children with special healthcare needs – a broad categorisation – we unavoidably included data that goes beyond our research question (McPherson *et al*, 1998). Another limitation is the exclusion of studies not in the English language. This limitation was agreed by both authors as we did not have access to a translation service.

Many of the US-based studies had large patient numbers, increasing their generalisability as representative of the US population. However, since many of these studies examine the relationship between health insurance status and healthcare access, this may limit their application to populations in other countries without health insurance systems.

Apart from the large North American studies included in this review, the majority of studies have looked at small, localised samples. We believe that larger, more systematic surveys are required. These could be done as cross-sectional surveys using large consolidated databases derived from general practice health records.

Practical health provision recommendations

The complicated and interdependent factors in providing health care to disabled people require complex solutions. The UK

National Service Framework for Long-term Conditions describes how health and social services should support people with long-term neurological conditions to live as independently as possible (Department of Health, 2005b). Although the *National Service Framework* focuses on people with long-term neurological conditions, much of the guidance it offers can apply to anyone living with a long-term condition.

Disability discrimination legislation across Europe requires providers of goods, facilities and services to make adjustments to their premises to enhance access for disabled people to ensure physical access (Whittle, 2002; HM Government, 2010). Incentives for general practitioners to keep registers of people with special needs would be a move in the right direction.

Clear leadership is required at national level from Departments of Health, with health authority accountability (Ali & Hassiotis, 2008). Health care for disabled people needs to be appropriate, efficient and effective, with co-ordinated medical, social, educational and vocational services, with good communication between primary and secondary care (Lawthers *et al*, 2003).

There has to be a clear responsibility for health care for disabled people that co-ordinates specialist and general care. Improved disability education would be an important first step (Byron *et al*, 2006; General Medical Council, 2003; Rohrer *et al*, 2008). The General Medical Council includes teaching on disability issues as one of the core elements to undergraduate medical school teaching (General Medical Council, 2003). Speech and language therapists could teach primary care staff strategies to improve communication with people with cognitive or communication impairments (Murphy, 2006). Patients' medical care may benefit from using a comprehensive patient and carer health assessment programme (CHAP). It enables specialists unfamiliar with a person's general healthcare needs, and general practitioners unfamiliar with the details of a specific disabling condition, to regularly review disabled patients (Lennox *et al*, 2007).

Improvements need to be monitored to ensure continued compliance. Local champions will need to perform robust audits of physical access in general practices and hospitals (Turner-Stokes *et al*, 2000). Accessible local transport could improve patient's attendance at clinics and even home-based primary care for disabled people can improve satisfaction with health care (Hughes *et al*, 2000). Each general practice surgery needs the necessary equipment to treat people with activity limitations, such as adjustable height examination couches, hoists and wheelchair weighing scales. Finally, payment for services needs to be linked to healthcare outcomes that are responsive to the needs of disabled people and do not treat their health care as the exception to the rule (Steel *et al*, 2008).

Although our review has focused on healthcare issues, we feel that limited access to health care may well have a knock-on effect on the use of social services by disabled people. Furthermore, many of the issues we have highlighted that affect access to health care will also affect access to social services.

Address for correspondence

Dr Jeremy C Gibson
Department of Rehabilitation Medicine
Royal Derby Hospital
Uttoxeter Road
Derby DE22 3NE
UK
Email: jeremygibson@doctors.org.uk

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