



## Examining a community model of epilepsy care for people with learning disabilities

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### Summary

*Purpose:* To assess the use of specialised medical epilepsy services by people with learning disabilities (LD) and epilepsy in a community healthcare setting, to compare medical epilepsy care in this group to current management guidelines, and to contrast important outcomes with those achieved in different healthcare settings.

*Methods:* Postal survey with a carer completed questionnaire addressed to all adults with epilepsy registered on an LD register in Sheffield, UK ( $n = 442$ ).

*Results:* An analysis based on 225 returned questionnaires revealed that 22.7% of individuals with LD and epilepsy had been free of seizures for over 1 year. 95.1% were taking antiepileptic drugs (AEDs), 46.2% had had an EEG, and 41.3% a brain scan. 53.3% of diagnoses had been made by epilepsy experts, 38.7% of individuals with LD and epilepsy were under specialist review. Although patients with more severe epilepsy were more likely to be under specialist care, 60.6% of patients with ongoing seizures,

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57.9% with major seizures and 68.7% of individuals taken to hospital with prolonged had no access to specialist advice.

*Conclusion:* The proportion of people with LD who achieved seizure-control in the described population was lower than in all previously reported studies of LD patient groups. The poor outcome in terms of seizure-control, the lack of access to the epilepsy specialist service, and the apparent under-utilisation of investigations indicate that there are grounds for serious concern about this community model of medical epilepsy care for people with LD.

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In the last decade, the provision of community and hospital medical services has undergone rapid changes in many developed countries. In the UK, a number of recent healthcare reforms were intended to reduce the role of costly (and typically hospital-based) specialist service providers and to increase the scope of community medical services. As traditional referral routes and treatment responsibilities are redesigned and redistributed, "patient journeys" have become a particular focus of interest. Ideally, historical arrangements would not only be replaced by less expensive systems, but also by organisational structures, which would lead to improvements in the selection of patients referred to specialist services. This would focus limited specialist care resources on those patients who could benefit most.

Optimal "patient journeys" probably matter most in conditions or situations where patients may not be able to seek out the most appropriate services for themselves, for instance in the area of healthcare provision for people with learning disabilities (LD).

In some ways, the disestablishment of specialised LD residential care facilities has led the way for changes in many other areas of healthcare provision. For instance, in one area in the UK, 54% of people with LD lived in specialist hospital accommodation in 1983, and only 6% in 1995.<sup>1</sup> This means that the examination of an established model of community care for people with LD may offer important insights into the potential benefits and pitfalls of similar healthcare delivery models in other areas.

The arrangements put in place for people with LD in Sheffield, UK, in the 1970s placed particular emphasis on the integration of people with LD into general healthcare services. In this model, most medical care needs are addressed in a community setting, and the General Practitioner (GP) becomes the primary medical point of contact. Usual care is supplemented by multidisciplinary Community Learning Disability Teams covering certain geographical areas and consisting of physiotherapists, occupational therapists, psychologists, speech and language therapists, social workers and specialist

nurses in LD. Although these teams have no direct referral rights to epilepsy specialist services they are intended to ensure that all of the patients' healthcare needs are met, using the GP to secure access to specialist advice if necessary. The Community Learning Disability Teams belong to the Joint Learning Disabilities Service (JLDS), which is part of the community mental health service. It retains a small medical LD service staffed with one psychiatrist with an interest in LD and a seven-bedded assessment and treatment unit (ATU) with a primarily psychiatric focus. It is the remit of the ATU to provide assessment and treatment of individuals with significant LD with challenging behaviour or comorbid psychiatric disorders. There is no access to EEG or video-telemetry. The JLDS also has access to five beds on a general psychiatric ward for people with mental disorders and less severe LD. Finally there are 15 designated beds for individuals with LD and complex health needs, which form the health component of an integrated respite service.

The hospital-based specialist epilepsy service consists of four consultant neurologists with access to relevant investigations including magnetic resonance imaging under general anaesthesia and epilepsy specialist nurses (who will only advise patients under the current care of a neurologist). Although the National Health Service is essentially the only purchaser of medical services for individuals with LD, the healthcare providers described here belong to different organisation with independent budgets (community mental health services, medical hospital services and several primary care organisations). The introduction of this model of community care was supported by a database (Sheffield Case Register) held by the local provider of mental health services which shares information with social and educational services and contains details of people with more severe LD.

We conducted a postal survey to find out more about the health services utilisation of people with LD and epilepsy on the Sheffield Case Register, and how service use relates to current management guidelines for epilepsy.<sup>2,3</sup> We also examined whether patients with the greatest need have

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