



Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications

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Summary

Statement of the problem: The prevalence of epilepsy in people with an intellectual disability (ID) is apparently higher than in the general population. The outlook for individuals with both epilepsy and ID depends on the presence of any associated conditions. However, there have been few epidemiological studies of the prevalence of epilepsy and associated problems within a representative adult ID population to inform the development of policy.

Method: This was a population-based prevalence study using the Leicestershire Learning Disability Register. Prevalence was estimated from the number of individuals with reported epilepsy identified from structured home interviews with carers. Associations with epilepsy were investigated for a range of defined physical, mental and skill attributes. Logistic regression was done with and without adjustment for age, sex and level of understanding to identify specific and holistic links respectively.

Results: The prevalence of epilepsy was 26%. Among those with epilepsy, 68% experienced seizures despite anti-epileptic medication. Epilepsy showed a significant association with low levels of understanding. Specific morbid associations included wetting (adjusted odds ratio 2.7), soiling (2.2), walking (2.5), daily living skills (1.6), poor speech (2.2), lack of empathy (1.5), mood swings (1.5), being uncooperative (1.6), seeking attention (1.7) and disturbing others at night (1.9). Holistic associations included a wider range of physical and mental problems and global skills deficits.

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Conclusions: The high prevalence, associated morbidities and global skills deficits make epilepsy care for adults with ID important and complex. Specialist epilepsy services for this population need a multidisciplinary skills mix.

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Introduction

The prevalence of epilepsy in people with an intellectual disability (ID) appears to be much higher than in the general population.^{1–11} However, most of the previous studies have been confined to children with ID and cannot be generalised to adults with ID because of potential developments in later life. Community-based studies of epilepsy in adults with ID show a prevalence of 16–26%.^{1,5,10,11} A review of existing studies highlighted the methodological problems, particularly case ascertainment and selection bias.¹² It is important to establish the extent of inequality in the prevalence of epilepsy between a representative group of adults with ID and the general population as a basis for providing equitable services for the socially neglected ID population.

Clinical studies of adults with ID have identified higher rates of behaviour and psychological problems in those who also have epilepsy compared with those without epilepsy.^{13–15} However, there have been few epidemiological studies of morbidity associated with epilepsy in the adult ID population as a whole. Knowledge of physical and mental health problems specifically associated with epilepsy in adults with ID may improve understanding of co-morbid connections and help to focus therapeutic efforts.

Both epilepsy and ID may be caused by a range of genetic, congenital, traumatic and other pathological processes.^{1,2,5} The risk of epilepsy is greater in those with additional neurological impairments as well as ID.⁶ It is generally accepted that epilepsy arises secondarily to brain damage or abnormality, which is the presumed cause of ID, but the precise relationship between ID and epilepsy is not always clear.^{1,8} It is important to identify factors related to the individual as a whole, incorporating both epilepsy and ID, as a basis for planning and delivering services.

The outlook for people with both epilepsy and ID varies according to the underlying and associated conditions.^{5,6,16,17} The latter include adaptive behaviour problems, which manifest as a lack of skills essential for living in our complex society.¹⁵ These have implications both for the management of individual patients and for planning services for those with multiple disabilities.

A key principle of the government's white paper *Valuing People*¹⁸ is to enable people with ID to access mainstream services. However, professionals in primary care may have limited knowledge and

experience of managing people with ID or epilepsy.¹⁹ Services for epilepsy in the UK are highly variable and few are orientated towards the needs of individuals with ID.²⁰ Psychiatrists in specialist ID services often lack experience of diagnosing and managing epilepsy. An epidemiological perspective on the extent of epilepsy in adults with ID and factors specifically and holistically associated with it may inform the debate about the mix of appropriate service provision for this group.

The aims of the study were to estimate the prevalence of epilepsy in adults with ID; and, among adults with ID, to compare the frequency of overall and specific physical disabilities, deficits in daily living skills, autistic traits, psychological symptoms and behaviour problems in those with and without epilepsy.

Method

This was a population-based prevalence study. The Leicestershire Learning Disability Register was used to identify adults with ID resident within the unitary authorities of Leicester City, Leicestershire and Rutland. The register was set up in 1987 to provide a sampling frame for research and a range of high quality epidemiological information to assist service planning and delivery.²¹ ID is defined as a moderate, severe or profound developmental intellectual impairment²² with associated adaptive behaviour problems²³ and a likely need for long-term support. Adults aged 19 and over with ID who are known to specialist health or social services are continually notified to the register by a comprehensive network of service providers using methods similar to earlier UK registers.²⁴ Ascertainment for the register using capture–recapture methodology is estimated to be 95%.²⁵

Detailed information is collected by specially trained interviewers in a 5-year rolling programme of structured home interviews with carers.²⁶ This includes the Disability Assessment Schedule,²⁷ which covers physical disabilities, daily living skills, level of understanding, behaviour problems and autistic traits based on the characteristics proposed by Wing.²⁸ Psychological symptoms were incorporated into the questionnaire before any validated instruments had been developed and were based on the clinical experience of psychiatrists at the time.

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