



# Implementing epilepsy guidelines within a learning disability service

Esther. Whitten\*, Andrew Griffiths

Sandwell Mental Health NHS and Social Care Trust, Heath Lane Hospital, West Bromwich, West Midlands, United Kingdom

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## KEYWORDS

Learning disability;  
Epilepsy;  
NICE guidelines;  
Implementation;  
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## Summary

*Purpose:* To investigate the usefulness of the implementation of NICE guidelines when reviewing care within an outpatient learning disability service.

*Methods:* We set up a multi disciplinary specialist epilepsy clinic and reviewed all patients with a diagnosis of epilepsy using a specific assessment document based on NICE guidance. We then audited clinical documentation prior to and after the implementation of the clinic.

*Results:* We reviewed 23 patients and found that implementing NICE guidelines showed improvements to individuals' seizure assessments and epilepsy management. When comparing specific areas related to NICE implementation we found that 83% compared to 6% of patients had accurate name and detailed seizure descriptions. We made changes to seizure diagnosis in 76% of patients and improved the level of recording of seizure frequency and severity. Finally 91% compared to 50% of consultations led to changes in treatment plans.

*Conclusion:* We found that implementing the NICE guidelines allowed us to use a systematic approach to epilepsy management, which in turn led to identifiable improvement in documentation and patient care.

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## Introduction

### Learning disability

The World Health Organisation<sup>1</sup> defines learning disability (mental retardation) as, a condition of arrested or incomplete development of the mind

characterised by the impairment of skills and overall intelligence in areas such as cognition, language, motor and social abilities. The individual severity of learning disability may vary as detailed below (Table 1).

### Epilepsy and learning disability

The relationship between epilepsy and learning disability is complex. Some specific epilepsy syndromes

\* Corresponding author. Tel.: +44 1216128450.  
E-mail address: esther.whitten@smhsct.nhs.uk (E. Whitten).

**Table 1**

Severity of learning disability	IQ range	Mental age
Mild	50–69	9 to under 12 years
Moderate	35–49	6 to under 9 years
Severe	20–34	3 to under 6 years
Profound	Below 20	Below 3 years

Adapted from ICD 10, Chapter 5.

are associated with learning disabilities, for example Lennox–Gastaut syndrome. Epilepsy is 20 times more common in people with a learning disability than the general population. The prevalence of epilepsy has a direct link to the severity of learning disability. The risk of epilepsy rises from 7% with mild learning disability to as high as 67% if the person has severe learning disability.

Diagnosis of seizure type can be extremely difficult in individuals with a learning disability. Seizures do not always conform to classic definitions and seizure activity needs to be differentiated from stereotypical behaviours.<sup>2,3</sup> This is exacerbated by the possibility of communication difficulties. Investigations may be more difficult to complete.

People with a learning disability are more likely to have<sup>4</sup>:

- More than one seizure type.
- Treatment resistant epilepsy.
- Prescribed polytherapy.
- Susceptibility to unidentified side effects of AED's.

### Clinical guidelines

The NICE guidelines aim to give advice about the diagnosis, investigation and management of epilepsy.<sup>5</sup> They make specific reference to people with a learning disability highlighting the importance of risk assessment and specialist multi disciplinary working.

They were predated by various learning disability specific documents. The Valuing People document and IASSID clinical guidelines both make reference to epilepsy management.

Frost et al.<sup>6</sup> stated that, guidelines are of little use if they are not recognised, implemented and supported. The study was therefore designed to investigate the above statement with reference to the NICE guidelines.

### Services that were in place prior to setting up the clinic

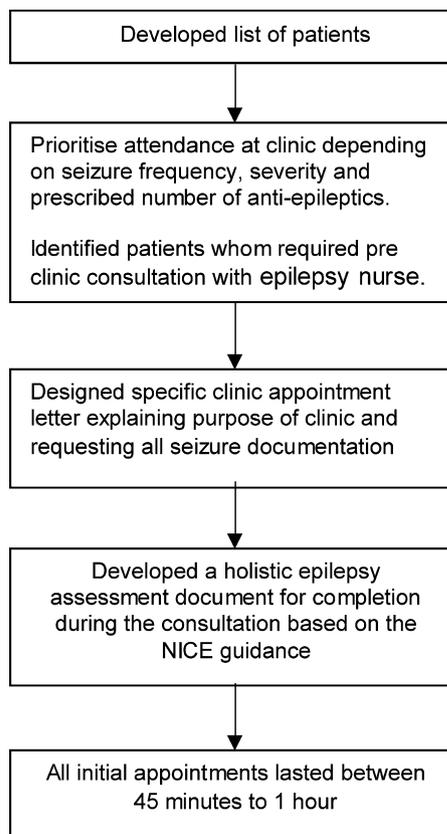
Prior to the start of this study patients were seen at the learning disability mental health outpatient clinic. This clinic focused primarily on mental health disorders.

There was no identified database of people whom attended for management of their epilepsy. Therefore the first task was identifying these people within the general outpatient population.

### Objectives of the clinic and the audit

- To carry out a multi disciplinary review of epilepsy care in line with NICE guidelines.
- To achieve a detailed record of past and present epilepsy care and update treatment and management plans.
- A comparison of clinical documentation before and after the introduction of the NICE guidelines.
- An assessment of the practicality of implementing the NICE guidelines.
- Suggesting relevant recommendations arising from the audit.
- To raise awareness of the NICE guidelines.

### Process of initiating the NICE clinic



### Methodology

The guidelines were implemented through the introduction of a specialist multi disciplinary epilepsy clinic.

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