

## Adults with learning disabilities and epilepsy: knowledge about epilepsy before and after an educational package

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The understanding individuals have about their epilepsy may influence the success with which that individual copes with his/her epilepsy. This paper presents the first evaluation of a video-assisted brief educational package for adults with mild learning disabilities and epilepsy ('Epilepsy and You'; Paul, 1996<sup>21</sup>). Utilizing a deferred entry to treatment design to evaluate intervention effects eighteen subjects participated in the study. Their knowledge about epilepsy before and after training was assessed using a checklist of knowledge and the Epilepsy Knowledge Questionnaire—Revised for use with people with learning disabilities. Results demonstrated significant gains in knowledge which were durable over a short follow-up period (1 month). 'Epilepsy and You' was found to be suitable for use with a wide range of individuals and subjects' opinions demonstrated they enjoyed taking part. This study is a preliminary investigation from which other research can develop. Therefore, criticisms and suggestions for further research have been made.

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### INTRODUCTION

Around 20 percent of people with a learning disability (mental retardation) have at least one seizure per year, and prevalence of epilepsy appears to be correlated with level of learning disability, with approximately 50 percent of individuals with a severe or profound learning disability having epilepsy<sup>1–3</sup>. This is considerably higher than the estimated 1 percent epilepsy prevalence in the general population. In addition, more severe levels of learning disability are associated with comparatively more mixed seizure presentation<sup>4,5</sup>.

Epilepsy is episodic, unpredictable and potentially dangerous which can lead to heightened anxiety. It can cause behaviours that others may perceive as 'abnormal', which can lead to a sufferer's perception of 'felt' or enacted stigma<sup>6</sup>. Although any psychological condition can occur in individuals with a learning disability<sup>3</sup> there is little research investigating the psychological consequences of having epilepsy for this population. Although Lund<sup>7</sup> originally suggested

psychiatric illness was more prevalent in individuals with epilepsy than those without the methodology of the study has since been criticized<sup>8–10</sup>. Furthermore, Deb and Hunter<sup>10</sup> found psychiatric illness was more prevalent in individuals who did not have epilepsy.

Following debate about whether there is an increased risk for behaviour disturbance<sup>1,11,12</sup> Espie *et al.*<sup>8</sup> concluded that '... Disturbed behaviour was not however, associated with epilepsy *per se*, but that '... the relatively small sub-group of subjects who have poorly controlled epilepsy do present greater behavioural management problems,' (p. 135). Gillies *et al.*<sup>9</sup> and Deb and Hunter<sup>13</sup> have supported these findings. No evidence for an increased risk of personality disorder has been found<sup>14</sup>.

The Commission for the Control of Epilepsy and its Consequences<sup>15</sup> has stated that 'the understanding that an individual has about any disability is directly related to the success the individual has in coping with the disability.' (p. 133). Although ignorance about epilepsy has been demonstrated in non-learning

Table 1: Distribution of subjects according to age, sex and cognitive functioning for treatment group and deferred treatment group.

	Treatment group ( <i>n</i> = 8)	Deferred treatment group ( <i>n</i> = 10)
<b>Age:</b>		
age range (years, months)	24, 0–46, 5	33, 4–68, 4
mean (years, months) ± SD (years, months)	36, 5 ± 7, 8	45, 8 ± 9, 11
<b>Sex:</b>		
male	5	5
female	3	5
<b>Cognitive functioning:</b>		
<b>Raven's Progressive Matrices raw score</b>		
range of raw scores	9–23	6–26
mean ± SD	14.50 ± 5.21	15.20 ± 6.73
<b>British Picture Vocabulary age score</b>		
age range (years, months)	2, 6–9, 10	2, 0–13, 0
mean (years, months) ± SD (years, months)	6, 0 ± 2, 11	5, 4 ± 3, 4

disabled individuals<sup>16–18</sup> no studies have investigated the level of knowledge adults with a learning disability have regarding their epilepsy.

Similarly, in the non-learning disabled population educational programmes have been effective<sup>19,20</sup>. But there have been no comparable studies in the learning disabled population. However, Paul<sup>21</sup> has produced a video-assisted training package ('Epilepsy and You') to help people with learning disabilities understand their epilepsy, and an epilepsy knowledge questionnaire for use with people with learning disabilities has been adapted from an existing measure<sup>22,23</sup>.

Despite the increased prevalence of epilepsy in the learning disabled population compared with the general population, there is no research investigating knowledge about epilepsy or how to preclude possible psychological consequences of epilepsy within the learning disabled population. The present study, therefore aims to;

- (1) Assess the level of knowledge about epilepsy and associated issues in adults with learning disability and epilepsy.
- (2) Determine whether participation in the 'Epilepsy and You' programme increases epilepsy knowledge, and whether any increase in knowledge is durable over time.
- (3) Examine whether any characteristics of those who benefit from 'Epilepsy and You' can be identified
- (4) Investigate users' opinions of 'Epilepsy and You'.

## MATERIALS AND METHODS

### Subjects

Eighteen subjects consented to participate in the research. Subjects were from adult training centres (*n* = 2), a residential village for adults with a learning disability (*n* = 3), a residential hostel for adults with a learning disability and epilepsy (*n* = 8) and an adult training centre for individuals with a learning disability and epilepsy (*n* = 5). The composition of groups involved in the procedure are detailed in the 'design' section of this article.

Inclusion criteria were; having a learning disability, at least one seizure during the preceding 12 months, being prescribed anti-epileptic drugs and having some capacity for verbal communication. Exclusion criteria comprised vision or hearing impairment, a diagnosis that further compromised cognitive processing (for example, dementia or autism) and previous participation in an epilepsy educational workshop. Summary descriptive information on the sample is presented in Table 1. This indicates that subjects were a mixed sex group of predominantly mildly intellectually disabled adults. In Table 2 seizure characteristics are described. The majority of subjects had refractory epilepsy and were being treated with anti-epileptic drug polytherapy.

### Measures

- (1) *British Picture Vocabulary Scale* (BPVS)<sup>24</sup>. This assessment was used to gain an indication of each subject's receptive vocabulary level.

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