

## **Employment: A summary of a UK examination of the Work Histories of People with Two Common Forms of EB.**

This study was planned in December 2007 to examine how proposed changes to the UK benefit system might impact on people with EB. It was undertaken by Mavis Hartley PhD, an experienced EB nurse.

The study set out to question a small sample of people with EB Simplex (EBS) and Dystrophic EB (DEB) about the effects EB had on employment/unemployment. It aimed to identify some of the difficulties encountered by people who struggle to maintain or obtain employment while coping with the constraints of their EB symptoms. It would also include exploration of dependency on benefits, working conditions and the nature of the jobs enjoyed by the happily employed.

It was envisaged that a clearer picture of the occupational, educational and training needs of the two groups would enable DebRA to offer advice and support regarding benefit and employment issues. It was also hoped that the findings would highlight possible preventative actions that could help those seeking to enjoy a fulfilling work life balance in which their specific needs would be recognised and addressed.

### **Study Description**

**The Design** used a semi structured interview approach.

**The Sample** was randomly drawn from those of working age in the population of the 1000 people registered with the DebRA EB National Survey. 60 subjects were selected to equally represent the two common forms of EB - 30 with EBS and 30 with DEB. (24 DDEB, 6 RDEB)

**The Instrument**, a questionnaire was designed to encourage the subjects to speak openly about aspects of their employment experiences education and training that they perceived as relevant. There was also opportunity for suggestions for improving the service DebRA offers to people with EB.

**Contact**, the interviewees were all previously known to the interviewer and were contacted by post or telephone.

**Venue**, the interviews were conducted either by telephone, or in a face to face conversation in the individuals home, depending on their preference. They were assured of anonymity and all interviews were undertaken by the writer.

**Timing** the interviews commenced in early February 2008 and were completed at the end of April 2008.

**Recording** all recordings were made by hand during the process of the interview, or in its immediate aftermath.

## **SUMMARY OF CONCLUSIONS**

Comparisons of the employed and unemployed across the groups show similarity. There was a tendency for more females to be unemployed. The imbalance of males to females made interpretation difficult but the frequency of stoical comments e.g. 'Grin and bear it' or 'ignoring pain', suggest evidence of a 'macho' determination to overcome difficulties. Such attitudes may stem from cultural influences that historically have placed males in the role of strong providers. The increased frustration the jobless men expressed appeared to support this theory.

Using Disability Living Allowance ( a UK benefit for people with mobility and/or care needs) to measure impairment indicated mobility difficulties in the EBS group, who described finding it hard to journey to work or obtain jobs that did not include excessive walking or standing. The DEB group were more likely to need the care component to finance supportive care in the activities of daily living.

There was some evidence in both groups of a disincentive to work because they could not earn sufficient to give up benefits. But in both groups the unemployed expressed a wish that they were able to work.

The work environment created problems for both groups who complained of employer ignorance of the difficulties EB presents. Despite their complaints many were not prepared to inform their managers of their condition, either because of embarrassment or fear of dismissal. Safety shoes and clothing presented problems for many but for others more comfortable brands have come on to the market that help to overcome the friction problems.

Many failed to consider the effects a new job but the fear of not being accepted if they disclose their EB may result in their failure to ask relevant questions regarding the demands of the job.

The examination of previous jobs showed a trend toward professional positions or self employment creating fewer problems. This is because they allow the freedom to avoid demanding tasks when the skin is particularly vulnerable.

Leaving full time education at the minimum age was the clearest indication of future employment difficulties. The EBS group were more likely to leave with no qualifications which led to them having little choice of jobs. This usually left them with two options - unemployment or manual jobs that require heavy lifting, working with machinery or standing for long periods, all conditions that have been shown to exacerbate blistering and pain.

There were also indications of a relationship between isolation at school and being open about EB and its effects as an adult. Frequent absenteeism and the effects of protective teachers sidelining children with EB so that they did not participate in sport and similar activities led to poor relationships with their peers who were then more likely to bully and marginalise them. This had

wider implications as there appeared to be links between non participation in school activities and later unemployment, poor social skills and secrecy about their condition in adult life.

There was a fairly wide consensus that being self employed, being based at home and preferably engaged in computer work was the ideal occupation for people with EBS or DEB.

### **RDEB specific issues**

Whilst those with RDEB shared many of the concerns of the DDEB respondents, there is individual evidence of high motivation and determination to overcome difficulties within this small group. However the findings show they are more acutely affected in terms of employment, education and social interaction.

The report shows half of them have never worked and do not anticipate ever having a job. All believed their education had been impaired by lack of understanding and isolation by teachers and peers, and those in work had often had to cope with considerable difficulties in order to maintain their jobs.

The findings also revealed all had experienced periods of loneliness and low self worth at some time in their life caused, they maintain, by bullying and embarrassment at school and in adult life.

### **Recommendations arising from the survey**

- A *DebRA* publicity drive is recommended aimed at informing and reassuring employers about EB in the workplace, with emphasis on what people with the condition can do, when provided with understanding and support.

A *DebRA* leaflet that could be handed out at job interviews, to resolve the issue of reluctance to embark on 'embarrassing' explanations. This would allow applicants to feel they have cleared the air and do not need to resort to secrecy - if appointed.

Teachers should be made aware of the long term effects of excluding children with EB from activities such as sport, drama or PE. Alternative roles should be provided that allow the children to maintain the respect of their peers. Sporting examples could include roles such as linesman, non playing captain, adviser on team strategy or assistant referee. In drama parts for wheelchair users can easily be devised and the role of prompter, scenery manager or sound engineer can provide positions of importance and status for the child with EB.

Parents too must be made aware of the isolating effect of frequent absences from school. Friendship groups quickly reform and exclude the child who is regularly missing from the group. While children with EB are inevitably too ill to attend school at times, absences for appointments at clinics,

surgeries and hospitals can whenever possible be reserved for school holidays or teacher training days. After-school shared interest groups can also help the child to form friendships which spill over into the school day.

NB In the following account the 24 people with DDEB and six with RDEB are generally referred to under the umbrella term DEB group. Separation according to genetic inheritance is only made when it is considered relevant.

The following report demonstrates that while those with RDEB share many of the concerns of the other 24 respondents, there is individual evidence of high motivation and determination to overcome difficulties within this small group. However the findings show they are more acutely affected in terms of employment, education and social interaction.

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***A fuller report on the survey can be obtained from DebRA UK***  
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