

## **EVIDENCE STORY FIVE**

### **RESPONSE TO 'DEATH BY INDIFFERENCE' - THE HEALTH REFERENCE GROUP, BEDFORDSHIRE LEARNING DISABILITY SERVICES**

#### **Introduction**

As a response to the MENCAP report 'Death by Indifference', a group of people with learning disabilities who make up the health reference group decided to look at what was happening in Bedfordshire by finding out what other people with learning disabilities felt about their experiences and how treatment has been improved in hospitals .

#### **Methodology**

The group made contact with service users in day centres in the county, advocacy groups and individuals who were known to want to make their views known about living in residential homes. The groups included people who were relatively able and with complex needs. Most of the groups needed three visits, highlighting the problems of communications they would have when staying in hospital.

Most people enjoyed the sessions they had with the group and felt strongly about their health needs and the fact that they were being asked about them. 70 people all in all gave their views

#### **Findings**

Seventy people gave their views and from these views 18 key principles were agreed which are in the full report which is available. The principles included:

- being listened to and treated with respect
- understanding how I communicate and have support in hospital to communicate if needed
- training for hospital staff to help them care for people with learning disabilities improve hospital policies
- support to people with complex needs
- the use of regular hospital checks and health action plans to maintain good health.

#### **Outcome**

As a result of this survey the group were able to provide evidence to the independent enquiry which was announced by the government as the result of the report death by indifference. The report has also influenced the development of a specialist health assessment report which is used in Bedfordshire to assess the health of people with learning disabilities. The report is also influencing Primary Care Trust practice in the commissioning of health services for people with learning disabilities

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