

# Learning Disabilities Mortality Review (LeDeR) Programme: Briefing Paper 1

## What do we mean by 'learning disabilities'?

Introduction

This document lays out the current most recognised definition of what it is to have a learning disability as well as some groups who do not fall within this delineation. It also explains who will and who will not be included in the LeDeR review programme.

**Briefing Notes** 

#### **Basic Definition**

A person with learning disabilities will have:

- A significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence) and
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development (Valuing People, DH 2001).

#### Who will be included in the LeDeR review programme?

Deaths of all people with learning disabilities aged 4 years and over will be reviewed as part of the Learning Disabilities Mortality Review (LeDeR) Programme. In order to help identify those who might have learning disabilities we suggest the following inclusion criteria:

Adults may be considered to have learning disabilities if any of the following conditions are met:

1. They have been identified as having learning disabilities on locally held learning disabilities registers (e.g. registers held by a GP or Clinical Commissioning Group) or by relevant Read Codes in health information systems



- 2. They are likely to screen positive for learning disabilities using a validated screening test
- 3. When a child they were identified within education services as having a Special Educational Need (SEN) associated with moderate, severe or profound learning difficulty
- 4. They attended a special school or unit for children with moderate, severe or profound learning difficulty or 'mental handicap'
- 5. As a child they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70)
- 6. As an adult they scored lower than two standard deviations below the mean on a validated test of general cognitive functioning and there is good evidence to suggest that they have had difficulties in learning since childhood
- 7. In response to survey questions, they may identify themselves as having a long-term illness, health condition or disability associated with 'learning disabilities' and may have low educational attainment (equivalent to no GCSEs at grade C or above).

**Children** may be considered to have learning disabilities if any of the following conditions are met:

- They have been identified as having learning disabilities on locally held learning disabilities
  registers (e.g. registers held by a GP or Clinical Commissioning Group) or by relevant Read Codes in
  health information systems
- They have been identified within education services as having a SEN associated with 'moderate learning difficulty', 'severe learning difficulty' or 'profound and multiple learning difficulty', or have been at the School Action Plus stage of assessment for this.

They have scored lower than two standard deviations below the mean on a validated test of general cognitive functioning (equivalent to an IQ score of less than 70).

#### Who will not be included in the LeDeR programme?

Some people with learning disabilities also have physical and/or sensory impairments, mental health problems or other neurodevelopment disorders such as autism. They would be included if they do have learning disabilities in addition to other impairments or disorders. People with Asperger's Syndrome are not included as they have average or above average intelligence and do not generally have learning disabilities as described above. People with brain injury or trauma sustained in adulthood would not fall within the definition of having learning disabilities because their impairment did not start before adulthood. People with dyslexia or other specific learning difficulties (e.g. dyspraxia) are not included.

#### Related terms

The UK is the only country that uses the term 'learning disabilities' in this way. Some countries (e.g. USA) use the term 'learning disabilities' to refer to people with 'specific learning difficulties' such as dyslexia. There is no overlap at all between these two uses of the term 'learning disabilities'. As such, evidence from the USA on services or interventions for people with 'learning disabilities' may have little or no relevance to policy or practice in relation to people with learning disabilities in the UK.

Many people with learning disabilities prefer to use the term 'learning difficulty' and the two terms are sometimes used interchangeably in common language and in the education system where the



#### term

'learning difficulty' also includes people who have 'specific learning difficulties' such as dyslexia.

The term 'intellectual disability' is often used in countries such as the USA or Canada and should be considered interchangeable with the UK term 'learning disabilities'.

### **Further Information**

Department of Health (2001). Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century.

World Health Organization (1992). The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. Geneva, WHO.

