Background There are an estimated 1.5 million people in the UK with a learning disability (LD), of which 351,000 are children (2.5% of total childhood population). It is recognised that for people with LDs to have the best life chance, early diagnosis and appropriate intervention in childhood is key. However, a formal diagnosis of LD may never be made despite a continuing acknowledgement of a child’s global development delay as they progress towards adulthood. Of those that are diagnosed, many do not receive recommended interventions, with only 55% of those registered as having an LD receiving their annual health check in primary care. 

Conclusions Confidence in diagnosing LD varies amongst clinicians. We call for the development of standardised pathways to assist with making a diagnosis. Clinicians used a range of tools and methods to assist with making a diagnosis including school reports, educational psychology reports, functional skills histories, IQ/WISC (The Wechsler Intelligence Scale for Children) diagnostic criteria used by the Centers for Disease Control. Not required for reporting. The case definition matches the diagnostic criteria used by the Centers for Disease Control.

Results There were a total of 148 notifications.

Exclusions
- 9 duplicates.
- 28 lost to follow-up.
- 10 data could no longer be provided.
- 34 notifying clinician felt case no longer met case definition.
- 19 excluded by authors (did not meet case definition).

Included 48 cases (38 probable, 10 confirmed).

- Confirmed and probable cases were analysed together.