A STRATEGY TO IDENTIFY YOUNG CHILDREN WITH DEVELOPMENTAL DISABILITIES VIA PRIMARY CARE RECORDS

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Background Electronic health records use clinical codes to classify disease and conditions, not disability (how impairment affects human function). Codes for the degree of disability are not routinely recorded alongside the diagnosis, unless part of the diagnostic code e.g. profound learning disability. Existing strategies identify conditions associated with disability, prioritising either identifying every person with possible or highly probable disability to limit type I (false positive) or type II (false negative) misclassification error.

In high income countries, 1–4% of children have developmental disabilities. They can be diagnosed before the age of five but, in practice, developmental delay is often diagnosed and the disabling condition (e.g. autism spectrum disorders or cerebral palsy) diagnosed when the child is older. Diagnoses of both delay/generalised developmental disorders and a disabling condition diagnosis could indicate disability severity. Is a sensitive or specific strategy or a combination of both necessary to obtain a realistic estimate of developmental disability prevalence in preschool children?

This study aimed to develop and compare strategies to identify children with possible and probable developmental disabilities diagnosed before the age of five in primary care data.

Methods Two case ascertainment strategies were developed and the primary care records of children in the Born in Bradford (BiB) cohort study (from birth to their fifth birthday) searched: 1) to identify children with conditions associated with substantial developmental disability (autism spectrum disorders, Down syndrome and cerebral palsy and moderate-profound learning disability); and 2) to identify children with indicators of developmental disability (developmental delay, generalised developmental disorders, mild and unknown severity learning disability).

Results The combined UK prevalence of the disabling conditions is 417 per 10,000 children below age 18. The prevalence in the study sample (n=9,727) was 85 per 10,000 (n=47 autism spectrum disorders, n=24 Down syndrome, n=12 cerebral palsy). None had moderate-profound learning disability. Half also had disability indicators (53%, n=44). The prevalence of disability indicators was 450 per 10,000 (n=438). Of those with only indicators (n=394), 75.9% had a single indicator. The most common indicators in both the condition and indicator groups were speech delay, developmental delay and developmental language delay.

Conclusion Using only disabling condition clinical codes for case ascertainment via primary care data is likely to greatly underestimate disability prevalence in children under the age of five. Where independent disability verification is not possible, the number of disability indicators may reflect disability severity.