

Diagnosis incidence of autism spectrum disorders is underestimated in Australian children, and there are inequalities in access to diagnosis and treatment services: a data linkage study of health service usage

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Introduction

The prevalence and diagnosis incidence of autism spectrum disorders (ASD) are difficult to determine. Estimates of ASD burden in Australia are produced from sample surveys of disability, and government records of welfare disability payments. While disability does affect many people with ASD, ASD itself is not a disability.

Objectives and Approach

We used government administrative records of health service use to more accurately estimate the number of children diagnosed with ASD. We also evaluated the health service pathways that are used for the diagnosis and treatment of ASD. The national Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) provide records of most health service usage and medication dispensing outside of public hospitals. These databases were linked for a random 10% sample of children aged ≥ 15 from 2008 to 2014. Unique codes identify some ASD-specific health service encounters, including assessment, diagnosis and treatment sessions.

Results

In 2014, MBS claims for ASD diagnosis were processed for an estimated 8,770 Australian children, an incidence of 18.6 per 10,000. This is 16% and 31% higher than estimates from disability surveys, and disability welfare records, respectively. True ASD incidence is likely to be higher still, as some ASDs are diagnosed in public hospitals, and are not recorded in our data. The gold standard for ASD diagnosis is a multidisciplinary team, however, only 25.6% of those diagnosed with ASD used government-subsidised multi-disciplinary assessment services. Among those diagnosed with ASD, only 32.3% of children accessed government-subsidised long-term specialist and allied health treatment services. Children diagnosed with ASD use significantly more PBS-listed medications compared to the general population, though there is no gold-standard pharmaceutical treatment for ASD.

Conclusion/Implications

The diagnosis incidence of ASD in Australian children is higher than previously estimated. The prevalence of ASD is therefore also underestimated. Multidisciplinary ASD assessment and treatment services are underutilised, likely due to out-of-pocket co-payments reducing affordability. These findings have significant implications for government health service planning for ASD.

