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Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults

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A B S T R A C T

Aims: To identify the main factors predicting delays in diagnosis for Autism Spectrum Disorder (ASD) at three stages in the diagnostic process: wait for first appointment; assessment duration, and total wait for diagnosis.
Method: Data were gathered from 150 case notes (80 child and 70 adult cases) from 16 diagnosing services across Scotland.
Results: Having more information pre-assessment was associated with a reduced duration of the diagnostic process for children. This relationship was partially mediated by a reduction in the number of contacts required for diagnosis. In adults, having more factors associated with ASD (increased risk) reduced the wait time from referral to first appointment, but increased the overall duration of the diagnostic process. The latter relationship was partially mediated by an increase in the number of contacts required for diagnosis.
Conclusion: Within children's services, increasing the amount of relevant information available pre-assessment is likely to reduce total duration of the assessment process by reducing number of contacts required. Having a high risk of ASD as an adult appears to result in being seen more quickly following referral, but also to increase the number of contacts needed and assessment duration. As a result, it increases and total duration overall.

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What this paper adds

There is a need to improve the process of assessment and diagnosis of ASD in both adults and children, and guidance exists for clinicians as to what constitutes best practice in this area. There is, however, a dearth of evidence, both nationally and internationally, about what causes delays in the diagnostic process and which models for ASD assessment and diagnosis are optimal. The present study provides some preliminary data about the main factors predicting delays in diagnosis for

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Autism Spectrum Disorder (ASD) at three stages in the diagnostic process: wait for first appointment; assessment duration, and total wait for diagnosis. This information is likely to be useful in guiding future research and in designing interventions to reduce wait times.

1. Introduction

Autism Spectrum Disorder (ASD) is a lifelong developmental disorder, with estimated prevalence in both children and adults of approximately 1% (Allison, Auyeung, & Baron-Cohen, 2012; Brugha et al., 2012). A high proportion of people with ASD also have an intellectual disability, with studies estimating co-morbidity of between 50 and 70% (Matson & Shoemaker, 2009).

Waiting times are utilised as an indicator of service performance in Europe, Australia, Canada and the USA (see Bowers, 2011 for an overview) and long waiting times can present a barrier to prompt diagnosis of ASD. This represents an international challenge, given the importance of early diagnosis in ensuring that the individual has access to appropriate support and resources (Goin & Myers, 2004) and in reducing parental stress (Mansell & Morris, 2004). Many parents, however, express dissatisfaction with the diagnostic process and experience it as stressful, slow and poorly managed (Mansell & Morris, 2004; Goin-Kochel, Mackintosh, & Myers, 2006; Osborne & Reed, 2008). Despite the availability of guidance about what individuals should expect in terms of diagnostic waiting times (Le Couteur, 2003), they have been found to be increasing (Mansell & Morris, 2004) and two thirds of child development teams in the UK were unable to provide a defined timescale for the completion of ASD diagnostic assessment (Palmer, Ketteridge, Parr, Baird, & Le Couteur, 2011). Delayed diagnosis can extend well into adulthood for many people with ASD (Brugha et al., 2011; Taylor & Marrable, 2011).

There is, therefore, a need to improve the process of assessment and diagnosis of ASD in both adults and children, and guidance now exists for clinicians as to what constitutes best practice in this area (Scottish Intercollegiate Guidelines Network [SIGN], 2007; National Institute for Health and Clinical Excellence [NICE], 2011, 2012). There is, however, a dearth of evidence, both nationally and internationally, about what causes delays in the diagnostic process and which models for ASD assessment and diagnosis are optimal (SIGN, 2007; NICE, 2012) and a resultant recognition of the need for research in this area (NICE, 2012). Due to the limited a priori knowledge of which factors are related to waiting times for diagnosis of ASD, we did not have pre-specified hypotheses; rather we attempted to develop hypotheses based on the data, in an exploratory manner. We, therefore, aimed to identify the most important variables which might impact independently on waiting times, assessment duration, and total duration from referral to diagnosis for child and adult ASD diagnostic services. This information is likely to be useful in guiding future research and in designing interventions to reduce wait times.

2. Method

2.1. Ethical approval

Approval for the study was obtained by the Caldicott Guardian and the Research and Development Departments of the participating services.

2.2. Design

The research design was a cross-sectional, retrospective case note study of eight adult and eight child ASD diagnostic services.

2.3. Participating services

As there was no comprehensive list of Scottish diagnosing services in existence at the time of the study, a sampling frame was generated from a broad range of sources inclusive of: the National Autistic Society's UK-wide Autism Services Directory Website, the NHS Education for Scotland Directory, Information Services Division, Health Education and Voluntary Sector networks, Scottish Government, and a comprehensive web search. A telephone survey was then conducted using this comprehensive list to ascertain which services routinely conducted diagnostic assessment of individuals with ASD (i.e. conducted 10 or more diagnostic assessments per year). In total, 53 child services and 15 adult were identified. Proportionate stratified random sampling, based on classifying each service as 'urban' or 'rural' according to postcode, was used to obtain a sample of 16 services (eight child and eight adult) which routinely assess for ASD and which were representative of the urban-rural configuration of Scotland.

2.4. Participants

The case note inclusion criteria were that the individual had received a diagnosis of ASD (inclusive of Autism, Asperger's Disorder, Autism Spectrum Condition, Autistic Spectrum Disorder) and had been diagnosed by the participating service within the past 24 months. Information was obtained from 80 child and 70 adult case notes. The smaller number of adult case notes was due to a number of the adult services having insufficient cases that had received a positive diagnosis of ASD