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Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children

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ABSTRACT

Background: This paper reports on the development of child and adult Action Plans for Autism Spectrum Disorder to address the problem of delayed diagnosis and lengthy waiting times. Evidence used in the development of action plans was gathered from a sequential mixed methods study to further understand the reasons for the long waiting time and potential solutions. This is the first published investigation, from the perspective of diagnosing professional teams, of the reasons for delays, which also generates solutions.
Methods: Ninety five clinicians from 8 child and 8 adult services attended 16 focus groups to explore clinicians' views on a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines. During focus groups, quantitative data were fed back, used to frame discussions and facilitate solution focused action planning with each service. Sixteen local action plans were synthesised to create an ASD Action Plan for children and an ASD Action Plan for adults.
Results: Key solutions are proposed to support the reduction of the wait for diagnostic assessment, through reducing non-attendance rates, reducing inappropriate referrals, developing efficient working and communication and improving the effectiveness of care pathways. These are presented in actions plans for use by clinical teams.
Conclusion: The first step in addressing the clinical challenge of increased wait for diagnostic assessment of ASD is understanding the complex and multi-factorial reasons for delays. The action plans developed here through systematic enquiry and synthesis may provide clinical diagnostic teams with evidence based guidance on common challenges and solutions to guide future quality improvement programmes. Future research to evaluate whether using Action Plans leads to a reduction in waiting times would be of value.
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1. Introduction

The international dilemma of increasing demand for assessment of Autism Spectrum Disorder (ASD) (Baio, 2012), together with the lengthy duration of the diagnostic assessment process (Matson, Beighley, & Turygin, 2012) can lead to delayed diagnosis and dissatisfaction with services (Crane, Chester, Goddard, Henry & Hill, 2016; Moh & Magiati, 2012). Clinical guidelines advise health professionals on components of a quality diagnostic assessment (NICE, 2011, 2012; SIGN, 2007). There is, however, little evidence based guidance for clinicians which offers ways of improving efficiency and reducing the wait for diagnosis of ASD, while adhering to clinical guidelines (McClure, Mackay, Mamdani, & McCaughey, 2010).

Pathways for diagnostic assessment have discrete stages (Le Couteur, Baird, & Mills, 2003; NICE, 2015) and there is evidence of the benefits of investigating solutions aimed at improving efficiency at each stage (Radnor, Holweg, & Waring, 2012). In the United Kingdom (UK) the recommended timescale for diagnostic assessment of children is no longer than 119 days (17 weeks) from referral for ASD assessment to diagnosis being shared (Le Couteur, Baird et al., 2003), however, only some child services meet this standard (Palmer, Ketteridge, Parr, Baird, & Le Couteur, 2011). Currently, no recommended standard is in place for adults in the UK. In Scotland, although adherence to evidence based clinical guidelines is high and is unrelated to waiting times (McKenzie et al., 2015a, 2016) there is currently a long wait for diagnosis of ASD (McKenzie et al., 2015b), with 74% of child and 59% of adult services exceeding the 119 day standard.

Only limited research exists about the factors that may impact on waiting times for ASD diagnosis and this suggests that these differ for adults and children. Having more information about children prior to diagnosis was associated with shorter assessment durations. In adults, the presence of risk factors for ASD (e.g. intellectual disability) was associated with a shorter wait between referral and first appointment; however, it was also associated with a longer assessment duration and greater number of contacts (McKenzie et al., 2015b).

More effective solutions to reducing waits arise when clinicians are consulted and included in a multi-faceted process of change (Melton, Forsyth, & Freeth, 2012). Quality improvement science offers methods and frameworks to support the adoption of evidence based practice (Meyers, Durlak, & Wandersman, 2012) and audit feedback, critical reflection and action planning are considered useful strategies in the planning stage of practice change (Vachon et al., 2015). Despite the value placed on partnership working between researchers and practitioners to facilitate improved evidence based practice (Pentland et al., 2011), the perspectives of clinicians working with individuals with ASD are rarely reported (Rogers, Goddard, Hill, Henry, & Crane, 2015). In order to try to address this, we engaged in active dialogue with clinicians for the purpose of developing a deeper understanding of waiting times and to explore possible practical solutions to support local, evidence based service improvement. We used a mixed method approach, now commonly applied in healthcare research, which has potential for rigorous, methodologically sound studies leading to valid outcomes (Creswell, Klassen, Plano Clark, & Smith, 2011). The integration of quantitative findings from phase 1 of our study (McKenzie et al., 2015a) with qualitative research methods (Silverman, 2010), using focus groups, facilitated the gathering of rich data about the complexities of ASD clinical practice (Carbone, Behl, Azor, & Murphy, 2010). Action planning has been identified as an important step in ensuring that evidence gathered from clinical data is used to enable practice change (Husk, 2008). Through this approach we hoped to meet the objectives of our inquiry, while ensuring strong relevance to clinical practice (Lingard, Albert, & Levinson, 2008). The research adopted a social constructivist epistemological stance i.e. that our perceived reality is shaped by our culture and society (Lit & Shek 2002). From this perspective we attempted to understand, interpret and locate the 'meaning' of the results in the social and clinical context and community of practice within which the participants worked.

1.1. Objectives

- To explore the reasons clinicians give to explain long wait times for diagnosis for ASD.
- To identify clinicians views on the challenges and solutions to a) reducing the wait for diagnosis and b) providing a good quality diagnostic process with good adherence to clinical guidelines.
- To develop collaborative action plans for improving the efficiency and quality of the process of ASD diagnosis in child and adult services.

2. Methods

2.1. Ethical approval

The Caldicott Guardian and the research and development departments of the participating services granted approval for this study.

2.2. Context for the study

The study was part of the Scottish national Autism ACHIEVE Alliance study in which 16 (8 child and 8 adult) ASD diagnostic services participated and provided case note data on recently diagnosed individuals. Details of the services and

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