



The relation between practice that is consistent with NICE guideline 142 recommendations and waiting times within Autism Spectrum Disorder diagnostic services



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ABSTRACT

Background: This study explores the extent to which recommendations from the National Institute of Health and Care Excellence (NICE) 142 guidelines, section 9.2 (relating to identification, assessment and diagnosis) reflected existing routine clinical practice in Autism Spectrum Disorder (ASD) diagnosing services in Scotland; and whether there was a significant relation between routine practice which more closely reflected these recommendations and waiting times.

Method: A cross-sectional, retrospective case note analysis of recently diagnosed adults, in eight ASD services across Scotland.

Results: The study found that the existing practice of the participating services was consistent with 14 (maximum number) of the included recommendations in at least half of cases analysed (range 37–70 cases) and was not related to increased total waiting time for diagnosis.

Conclusion: The results, based only on the included recommendations, suggest that the section 9.2 recommendations can be integrated into clinical practice in Scotland with relative ease and that it is unlikely to have a negative impact on waiting times.

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1. Introduction

Timely diagnosis of Autism Spectrum Disorder (ASD) can help facilitate access to appropriate support for the individual and carers (Goin & Myers, 2004), however, there are high levels of dissatisfaction with the diagnostic process in terms of the time it takes to diagnose, the diagnostic process itself and post diagnostic support for both children (Crane, Chester, Goddard,

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Henry, & Hill, 2015) and adults (Jones, Goddard, Hill, Henry, & Crane, 2014). Two recent studies suggest that diagnostic practices, and the time taken to diagnose ASD in adults, vary widely across the UK (Jones et al., 2014; Lowenstein & Sutton, 2013) indicating a need for a more standardised and equitable approach.

Clinical guidelines aim to reduce service variations in the provision and quality of care (e.g. National Institute of Clinical Excellence [NICE], 2012)¹ and to improve the patient and carer experience and clinical outcomes by providing practitioners with an impartial structured summary and evaluation of the evidence base. NICE guidelines, while developed for use in England and Wales, are recognised and used internationally (NICE International, 2014). While organisations such as NICE are not without their critics (e.g. see Pearson & Rawlins (2005)), reviews of the impact of such guidelines suggest that they can be associated with a range of improved patient outcomes in health, such as better mental health and lower levels of post-natal depression compared with normal care (MacArthur et al., 2003) as well as having benefits for professionals and organisations, such as improved staff and patient satisfaction (see Bazian (2005) for an overview). Bazian (2005, p. 274), however, conducted a systematic review of research in this area and concluded that 'guidelines can work but often don't.'

One significant reason why clinical guidelines may not work is a lack of practitioner adherence to them. Research with practitioners working with a range of physical (e.g. Johansson, Pilhammar, Khalaf, & Willman, 2008) and mental health conditions (e.g. Currin et al., 2007), has found adherence to guidelines to be relatively low and to vary both within the same patient population (Goldman, Healy, Florence, Simpson, & Milner, 2003) and between different diagnostic groups within the same clinical practice (Van Fenema, Van Der Wee, Bauer, Witte, & Zitman, 2012). A number of barriers to adherence have been identified including limited practitioner awareness of guidelines which are relevant to their practice; a lack of consensus about how the terminology used in guidelines should be interpreted (e.g. Gyani, Shafran, & Rose, 2012; Rhodes, Genders, Owen, O'Hanlon, & Brown, 2010); insufficient training for professionals in their use and resistance to what are seen as prescriptive processes which conflict with clinical decision-making (Hirsch, 2003).

One of the common features that is shared by guidelines that have been successfully integrated into practice is that they are seen as making the process quicker and easier. Clinicians may, therefore, be unlikely to implement guidelines if they consider them to be introducing an additional time-consuming step in the process of providing care (Bazian, 2005) or require additional staff resources (Rhodes et al., 2010). These concerns are particularly pertinent in the context of a focus on reducing waiting times across the National Health Service in the UK (Department of Health [DOH], 2013; Scottish Government, 2011) and clinicians may be particularly reluctant to introduce guidelines which they feel may negatively impact on waiting times. It is, therefore, important to establish if practice that is consistent with guidelines is related to increased waiting times. Research has also indicated that guidelines that are successfully implemented reflect routine practice for the clinical group being targeted (Bazian, 2005).

In 2012 NICE developed guidelines on the identification, diagnosis and management of ASD in adults. Prior to their development no equivalent evidence base guidance existed for clinicians working in adult ASD services in Scotland, although guidance was available in relation to children (NICE, 2011; Scottish Intercollegiate Guidelines Network, 2007), and it was unknown to what extent the recommendations reflected existing practice there. The research reviewed above suggests that the NICE (2012) guideline had a greater chance of being routinely implemented in practice if it reflected existing practice and was not considered to increase waiting times.

The aims of the present paper were, therefore, to explore:

- a) the extent to which the section 9.2 recommendations of the NICE (2012) guidelines which relate to case identification, assessment and diagnosis, reflected existing routine clinical practice in ASD diagnosing services in Scotland.
- b) whether there was a significant relation between routine practice which more closely reflects the recommendations of the NICE (2012) guideline and increased waiting times.

2. Method

Ethical approval for the study was received from the Caldicott Guardian and the Research and Development Departments of the participating services.

2.1. Design

The study design was a cross-sectional, retrospective case note study of adult ASD diagnostic services in Scotland.

2.2. Participating services

Eight services participated. These were identified using proportionate stratified random sampling from a potential pool of 15 adult ASD diagnostic services in Scotland, and invited to participate. Stratification was based on the Scottish Government definition of urban/rural classification i.e. those services classified as 'urban' were contacted in order determined by the

¹ Now re-named National Institute of Health and Care Excellence.

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