EDITOR'S CHOICE

Autism spectrum disorder diagnostic assessments: improvements since publication of the National Autism Plan for Children

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Accepted 15 February 2010
Published Online First 3 June 2010

ABSTRACT

Objectives To assess in the context of a publically funded healthcare system, change in UK autism spectrum disorder (ASD) clinical diagnostic practice following the recommendations of the National Autism Plan for Children (NAP-C 2003).

Methods In 2007, a questionnaire based on standards from the NAP-C was sent to UK child development teams (CDTs); results were compared with 2001 data from the National Initiative for Autism Screening and Assessment.

Main findings Responses were received from 149 of 243 UK CDTs (61%). Most teams used standardised autism diagnostic assessments. There was greater access to members of the multidisciplinary team than in 2001. Only one-third of teams had a defined timescale for completion of assessment; of those teams, about half met the recommended NAP-C target.

Conclusions Since 2001, there has been an improvement in diagnostic services for children with ASD, however, inequalities remain. Providers should continue to improve services in order to deliver timely and comprehensive assessments for children with ASD.

INTRODUCTION

Autism spectrum disorders (ASDs) have an estimated prevalence of 1% in children.[1] In preparation for the National Autism Plan for Children (NAP-C), the National Initiative for Autism Screening and Assessment (NIASA) working group in 2001, received responses from 84% of separate UK child development teams (CDTs) and found widespread variation in clinical diagnostic and management services for children with ASD. Inequality of ASD assessment services within and between regions of the UK was clear; there was a lack of consensus about what constituted best practice in terms of assessment and diagnosis.[2] In an effort to improve ASD services across the UK, in 2003 the Royal College of Paediatrics and Child Health, the Royal College of Psychiatrists and other professional bodies endorsed the NAP-C.[2] The NAP-C recommended a possible template for a multidisciplinary, multi-agency approach to the assessment and diagnosis of children with suspected ASD. Guidance about acceptable waiting times before and between assessments, and appropriate resources which should be available as part of the diagnostic process was offered. These NAP-C recommendations have considerable resource implications for CDTs.

This study investigated using a national audit questionnaire, changes to UK autism diagnostic services since the publication of NAP-C.

METHOD

Taking account of the questions from the NIASA survey and the NAP-C recommendations, a questionnaire was designed to measure changes to UK ASD diagnostic services. In July 2007, questionnaires were sent electronically to the 243 UK CDTs then listed on the British Academy of Community Child Health/British Academy of Childhood Disability database; two reminders were subsequently sent. Data collection ended in November 2007. Respondents were asked their opinion of their service, whether they had experienced constraints, and whether there had been additional funding available since the NAP-C publication. Respondents were also asked to indicate which professionals were available to contribute to the assessment (if required). The audit questionnaire is available from the corresponding author on request. Approval to carry out this study was granted by Northumbria Healthcare NHS Trust.

In analysis, when possible, data about ASD diagnostic services were compared with those gathered by the 2001 NIASA working group. The aim of this study was to report overall change following publication of the NAP-C and between 2001 and 2007 not the practice of individual CDTs.

RESULTS

Completed responses were received from 149 of 243 CDTs (61%). Eighty-seven per cent of the 149 CDTs offered ASD assessments to preschool age children, and 77% to primary school age. Only 64% of CDTs were able to assess secondary school age children. Fifty-four per cent of CDTs had a formal written ASD assessment protocol compared with 32% in 2001. Sixty-six per cent had a protocol which described the pathway from general developmental to multidisciplinary ASD assessment, compared with 40% in 2001.

Only 36% of assessment teams had an agreed timescale for the completion of assessments. Of these teams 49% met the NAP-C recommended timescale of assessment completion in fewer than 30 weeks.

There was an increase in the number of CDTs using standardised diagnostic interviews (50% in 2007 vs 14% in 2001). Fifty-six per cent of CDTs used a published observational method of assessment compared with 14% in 2001; 88% of those using an observational tool used the Autism Diagnostic Observation Schedule.[3] Almost all assessment teams included a paediatrician, and there was a rise in the availability of other members of the multidisciplinary team (see table 1). Seventy-four per cent of CDTs gave multidisciplinary diagnostic feedback to parents, 92% gave parents a written diagnostic report and only 46% provided an agreed written care plan. Just over two-thirds of CDTs reported access to tertiary/secondary opinion ASD diagnostic services.

Only 9% of CDTs had received new funding for the assessment of children with ASD. Seventy-four per cent of respondents thought their service were effective.

DISCUSSION

This study describes in the context of the UK publically funded National Health Service (NHS) healthcare system, the autism diagnostic services provided by CDTs and the progress toward achieving the recommendations described in the NAP-C (2003). More than half the respondents now have clear assessment pathways. However, it is disappointing that only one-third of teams had a defined timescale during which assessment should be completed and of those teams, just under half were able to meet the target of 30 weeks. These data suggest that a majority of families with a child with ASD are waiting longer than suggested in the NAP-C for their child's diagnosis. Our findings should also be considered in relation to the current NHS 18 weeks target from patient referral to the commencement of treatment. While the effect on families was not a focus of this study, these delays in diagnosis are likely to cause families hardship, and in some cases reduce access to services and support. Perhaps most crucially, in some parts of the UK, access to ASD specific intervention strategies is dependent on a confirmed ASD diagnosis; this delay in diagnosis occurs at a time when interventions may ameliorate disability and improve functional outcomes.

The majority of CDTs now use one or more standardised autism diagnostic assessments during diagnosis. There is greater access to important members of the multidisciplinary team. For instance, educational psychologists are now represented in two-thirds of CDTs; this is particularly welcome as educational placement and intervention strategies are often the focus of parents' questions to health professionals. That one-quarter of CDTs do not offer parents a multidisciplinary feedback discussion is concerning. The recommendation made by NAP-C about written care plans for families has not been implemented by the majority of services.

Table 1 Change in methods and members of the multidisciplinary team (MST) available for autism spectrum disorder (ASD) assessment between 2001 and 2007

	2001 (%)	2007 (%)*
Team approach		
CDTs using MDT approach to ASD diagnostic assessment†	48	93
Joint clinics with child mental health services	34	57
Professional		
Educational psychologist	3	66
Occupational therapist	–	54
Clinical psychologist	47	53
Specialist teacher	–	52
Child psychiatrist	22	42
Physiotherapist	–	40
Social worker	15	30
Dietitian	–	23
Family support worker+	2	22
Learning disability psychiatrist	3	15

– Data unavailable from 2001; + parent counsellor in 2001. *% For each professional discipline, not number of sessions funded for the discipline. Many responders commented on lack of availability of particular professional groups. †At least speech and language therapist (SLT) and paediatrician. CDT, child development team.

The strengths of this study are that data were collected from across the UK, which increases the likelihood of gaining a representative view of current UK practice. Respondents were asked to report current service provision and highlight service/resource constraints, with the aim of encouraging responses from a representative sample of CDTs, and decrease the risk of reporting bias. There are likely to be several reasons why the response rates between 2001 and 2007 were different; one possible reason is that some clinicians did not respond as fewer than expected improvements had been made at their CDT. Conversely, clinicians whose services were not meeting NAP-C standards may have been more likely to respond, and draw attention to the increased need for resources. However, the findings of this survey robustly show that considerable improvements are still necessary in the assessment services offered by some CDTs. The study's limitations include that comparisons between 2001 and 2007 data cannot be made in all areas. Further, the changes described in this paper have taken place between 2001 and 2007 and therefore the extent to which the NAP-C (2003) contributed to the change cannot be fully assessed. Increased awareness about ASD, the increased number of detected cases and subsequent pressure on autism diagnostic services might have led to improvements without the NAP-C. Nonetheless, the NAP-C guidance has probably increased pressure on NHS Trusts and Primary Care Trusts (PCTs) to provide timely and comprehensive multidisciplinary diagnostic services.

Why might some services have been more successful at meeting the NAP-C recommendations than others? From responses we have received, and subsequent discussions following national presentations (RCPCH conference 2008[4]), teams meeting the NAP-C recommendations have rarely received more funding, but rather have reconfigured existing clinical services. Improved multiagency assessments were also reported, notably involvement of educational psychology. Several responders highlighted the limited capacity of specific disciplines to meet the clinical need (such as speech and language therapists) and suggested this may have contributed to delays in completion of assessments. Therefore, according to this study, modification alone, has not led to sufficient change in waiting times for assessment. It is likely that teams require additional clinical resources to ensure that children with ASD and their families receive equitable and timely access to diagnostic services.

Preece and Mott[5] highlighted the need for targets for the assessment of all children with neurodevelopmental disorders, rather than just focusing on children with ASD. Further data about diagnostic services for children with non ASD and autism spectrum developmental disorders will become available during 2010 following the UK British Academy of Childhood Disability CDT Survey (Jolleff, Parr and Gibbs, manuscript in preparation). With reference to ASD, the Scottish Intercollegiate Guideline Network recommendations[6] are likely to influence clinical practice in Scotland. The National Institute for Clinical Excellence guidelines for the assessment and diagnosis of children with ASD in England and Wales are expected in 2011. The National Institute for Clinical Excellence guidance is a further opportunity to address current discrepancies in service provision and ensure that children with ASD and their families access comprehensive diagnostic services in a timely manner.

Competing interest None.

Provenance and peer review Not commissioned; externally peer reviewed.

Contributors Jenna Charlton Research Assistant to Professor ALC at Newcastle University contributed to the referencing and format of the article.

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Arch Dis Child 2011 96: 473-475 originally published online June 3, 2010
doi: 10.1136/adc.2009.172825