Cost of assessing a child for possible autism spectrum disorder? An observational study of current practice in child development centres in the UK

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ABSTRACT

Objective UK guidelines recommend that diagnosis of autism in children requires assessment by a multidisciplinary team. With growing numbers of referrals for assessment, diagnostic services have been under increasing pressure to meet the level of need. This study aimed to explore the number of hours of professional time required to complete such an assessment based on current practice in secondary care child development centres across the UK, and from this we calculate the cost of assessment.

Design An online questionnaire, using SurveyMonkey, was sent to 20 child development centres asking them to retrospectively record team members involved at each stage of assessment and time taken, including report writing and administration for a typical assessment. Costs were estimated based on the hourly rate for each team member, including salary, on-costs and trust overheads.

Results 12 questionnaires (60%) were returned. 10 centres adopted a two-stage approach to assessment with an initial ‘screening’ clinic determining whether the child needed to proceed to full multidisciplinary assessment. Median professional time involved was 13 hours (IQR 9.6–15.5 hours). This resulted in a median cost of £809 ($1213, based on conversion rate £1 equal to US$1.5 (November 2015)), (IQR £684–£925) ($1026–$1388). The full process typically requires around 13 hours of professional time to complete, although initial ‘screening’ assessment only takes 1–2 hours. This costs around £800 (US$1200) per child for a completed diagnostic assessment.

Implications This study confirms that multidisciplinary diagnostic assessment of a child with possible autism requires significant professional time, with staff costs of approximately £800 ($1200) per child. This does not include costs of intervention, parent psychological education, investigation and assessment and management of comorbidities. If growing waiting times for diagnostic assessment are to be avoided, funding for diagnostic services needs to reflect the human resources required and the resulting costs of that assessment.

INTRODUCTION

Autism spectrum disorder (ASD) is redefined in the Diagnostic and Statistical Manual of Mental Disorders (DSM), Fifth Edition,¹ by the presence of ‘persistent deficits in social communication and social interaction across multiple contexts’ and ‘restricted, repetitive patterns of behavior [sic], interests, or activities’. The International Classification for Diseases (ICD) XI β² similarly suggests ‘ASD is characterized by persistent deficits in the ability to initiate and sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, inflexible patterns of behaviour and interests’. Presentation varies significantly, for example, the relative severity of deficits in social communication and repetitive behaviours¹ or associated intellectual levels or verbal abilities of the child.¹² With no confirmatory laboratory test, diagnosis requires building an accurate picture of the child across settings. The combination of complexity and increasing demand for diagnostic assessment for possible

What is already known on this topic?

► UK (National Institute for Health and Care Excellence) guidelines recommend that diagnostic assessment of a child for possible autistic spectrum disorder should be carried out by a multidisciplinary team.
► With increasing incidence of autistic spectrum disorder, there has been increasing demand on diagnostic services in the UK, resulting in long waiting times for assessment.
► Traditional funding of child development services by block contract has struggled to respond in a timely manner to increasing demand on these services.

What this study adds?

► Most secondary care child development centres taking part in this study adopted a two-stage process for assessment of a child with possible autistic spectrum disorder.
► The full process typically requires around 13 hours of professional time to complete, although initial ‘screening’ assessment only takes 1–2 hours.
► This costs around £800 (US$1200) per child for a completed diagnostic assessment.
ASD means services are coming under increasing pressure, resulting in long waiting times warranting a better understanding of professional time involved alongside resulting financial costs. Additionally, a clearer picture of diagnostic pathways is vital in informing appropriate future provision of services.

UK National Health Service (NHS) recommends diagnostic practice based on National Institute for Health and Clinical Excellence (NICE) guidelines developed following rigorous systematic review of the evidence base. Assessment by a multidisciplinary team including a core team of a paediatrician, speech therapist and psychologist is recommended as good clinical practice to determine whether a child meets diagnostic criteria in line with DSM IV, ICD 10 (as in this study) or now DSM V. Teams may be based in secondary care child development centres (CDC), whether in a local hospital or community setting, of which there are 179 in the UK, or Child and Adolescent Mental Health Services (CAMHS). Complex cases may also be referred to specialist tertiary centres, responsible for supporting secondary care services.

Alternative explanations of a child’s social communication, and associated comorbidities, may need to be identified, so NICE recommends that assessment of neurodevelopmental disorders (eg, developmental coordination disorder), mental and behavioural disorders (eg, ADHD and mood disorder), developmental regression (eg, Rett’s syndrome), ‘maltreatment’ and visual or hearing impairment should be considered. In addition to a core team, NICE advises access to other disciplines, for example, occupational therapy, to ‘construct a profile for each child or young person, for example (their) intellectual ability…speech, language and communication, fine and gross motor skills, and mental and emotional health including self-esteem’. Younger children are mostly assessed within CDCs in UK practice, presenting with concerns about neurodevelopment or developmental regression. As children approach adolescence, they often develop secondary mental health difficulties such as depression, and therefore may access child psychiatry and clinical psychology, mainly based in CAMHS services.

Use of validated formal structured history, such as the Autism Diagnostic Interview-Revised, and observation for autistic behaviours, for example, Autism Diagnostic Observation Scale (ADOS), is encouraged. However, NICE recognises that ‘no single tool alone [has] adequate sensitivity and specificity for diagnosis of autism’. While some countries have developed their own guidelines, others, for example, Australia, recognise NICE as ‘gold standard’. Most aspire to a multidisciplinary approach, which is not always achievable, such as when performed by a single practitioner or ‘office paediatrician’.

With changes in the way health services are financed in the UK, it was hoped a move to funding specific pathways with a tariff per patient would improve patient care. As Monitor comments:

The design of the payment system influences…quality of NHS care for patients in lots of ways. [T]he payment system…can make sure commissioning groups pay providers enough money to cover the costs of caring for patients…If commissioners pay providers of NHS services too little, they won’t be able to afford to give the high standards of care that patients need and have the right to expect.

However, community services within the UK NHS, including for ASD, continue to be resourced through block contracts. Budgets are allocated to providers to deliver a service such as a CDC but are less responsive to changing caseloads.

In the absence of national benchmarks for autism costs or agreed tariffs, the primary study aim was to calculate financial costs to the NHS of a typical multidisciplinary diagnostic assessment for a child with possible ASD. To achieve this, an additional main aim was to establish professional time involved in an ‘average’ pathway at secondary care CDCs across the UK. Secondary aims included determining typical numbers of children being seen in each centre, perceived likelihood of receiving a diagnosis of ASD and whether teams felt happy with the pathway offered. Multiple assessments and national numbers for other diagnoses were not considered.

Owing to the questions asked, no hypotheses were made.

METHOD
An online questionnaire, using SurveyMonkey.com, was sent to 20 CDCs identified through the British Association of Community Child Health Informatics Group (BACCH IG), approximately 11% of the UK total. Consultant paediatricians were approached through BACCH IG
where there was an interest in addressing the question of costs via pathways to care. The questionnaire (see box and online supplementary appendix 1) was designed to allow teams to report the amount of time spent by members of a multidisciplinary team in completing full diagnostic assessment. This included space to describe stages of assessment, for example, for teams who run an initial general developmental clinic or for observation in educational settings. Teams also reported on their satisfaction with their pathway. Respondents were all senior community or neurodisability paediatricians within a team. Teams were contacted after initial interest through email and were contacted once more by email if they did not respond. The study took place between January and May 2013.

Pathway costs were calculated by multiplying hourly unit costing of the different staff involved, based on ‘Unit Costs of Health and Social Care 2013’,14 by the amount of time each staff member contributed to a typical assessment (see online supplementary appendix 2 for example of calculation for one school age pathway). The unit costing is calculated from salary+salary on costs (14% of salary)+trust overheads+management (20%)+non-staff costs (50%)+capital overheads+travel+training costs.14

The study was approved by Brighton and Sussex Medical School Research Governance and Ethics Committee. Non-parametric statistical analysis was used, with simple descriptive data, including medians and IQRs, as results were not normally distributed and in anticipation of small sample size. Regression analysis was used to examine the relationships between variables.

RESULTS

An encouraging 12 out of 20 (60%) questionnaires were returned (see figure 1 for distribution of centres). One CDC only assessed preschool children, with older children referred to the CAMHS or tertiary centre. Two delivered a service for 0–11 year olds, six 0–16 years and three 0–19 years. Ten out of 12 CDCs provided initial assessment before progressing to full diagnostic assessment, if required. A median of 140 children (IQR 90–177.5) was assessed in each centre annually.

In the 10 centres running an initial assessment, median cost was £147 ($220) (IQR £116–£148). The median cost of a full assessment, including initial appointment, was £809 ($1213), (IQR £684–£925) (see figure 3). Cost was directly related to length of time taken in the assessment (r 0.82, P<0.002, see figure 4) but not to the number of professionals involved (r 0.24, P=0.45). Cost was also closely related to number of doctor hours contributing to the assessment (r 0.84, P=0.001, see figure 5) but not statistically significantly to hours of speech therapy (r 0.02, P=0.9) or clinical psychology (r 0.54, P=0.07). The proportion of children receiving an ASD diagnosis was negatively related to the number of hours taken in assessment (r −0.52, P=0.19), cost of assessment (r −0.16, P=0.71) and number of professionals involved (r −0.43, P=0.25), but none of these reached statistical significance.

Nine respondents commented that available resources governed diagnostic pathways often expressing a need to increase capacity. Two units expressed satisfaction with their current pathways. One unit commented on difficulties in meeting NICE guidelines, while another commented that an increase in referrals has led to shorter assessments.

Three CDCs regularly provided long-term follow-up care for families with a new diagnosis. Two reported continued involvement only for specific issues such as need for medication. Another unit commented on...
Figure 2  The number of staff from each discipline contributing to diagnostic assessment across the participating centres (OT short for occupational therapists, HV for health visitors).

its provision of short-term follow-up but experiencing increasing pressure to halt longer term follow-up. All centres could access other agencies for postdiagnosis input, for example, Early Bird programme.

DISCUSSION
This study reported the amount of time that goes into an assessment of a child with possible autism and suggests most UK centres spend around 13 hours per child, costing between £650 and £1000 ($975–$1500). The most expensive outlier, a school-age pathway, costing £1446 ($2169), was delivered by two consultants, a paediatrician and child psychiatrist, working together. This reflects doctors’ hourly rates being generally twice that of other members of a multidisciplinary team. Consequently, the length of time spent by doctors in diagnostic assessment also appeared to directly influence cost compared with other disciplines, with a similar impact to that of the total length of time spent by the whole team. This would suggest that carrying out a multidisciplinary assessment is a good practice and allowing allied health professionals to carry out parts of the assessment not requiring doctor’s skills, for example, observational assessment using ADOS, could save costs. While this study reflects current practice across the NHS, it did not set out to determine relative merits of individual pathways nor scrutinise whether variation in expense gave a more reliable outcome.

This study was based on what teams believed their typical pathway looks like rather than actual patient journeys. There is potential for recall bias, with participating centres potentially over, or under, estimating the length of time taken in a typical assessment. Some centres reported difficulty completing the questionnaire, as it did not fit their pathway. While the method for calculating costings is recommended by health economists in the UK and includes recognition of trust on-costs, overheads and training, it may underestimate additional costs such as report writing (although centres were encouraged to include this), material costs (eg, Autism Diagnostic Interview paperwork) and ongoing service development. The number of responding centres was small, representing 7% of CDCs in the UK. Nevertheless, most centres showed consistency in time taken and
Indeed post-diagnostic support.17 Identified in a recent survey of over 1000 parents around and families. This might also help to address concerns sive assessment required by NICE,3 16  commissioners demand while achieving the timeliness and comprehen-
ally, this might also enable teams to respond to growing
With growing capacity issues being identified internation-
rates of referral could allow services to develop their ideal
a multidisciplinary assessment and that is responsive to
funding model that reflects realistic costs for conducting
length of assessment and personnel across the country.
Most respondents stated that multidisciplinary pathways
were identified. While this is not yet recommended for
all children with ASD, this may become a routine, adding
significantly to the overall costs of diagnostic assessment.
Interestingly, the five exemplar pathways in NICE
guidelines1 have combined professional times ranging
from 16 to 49 hours. While these might reflect ideal
practice, respondents appear to reflect a more realistic
length of assessment and personnel across the country.
Most respondents stated that multidisciplinary pathways
depended on resources available to them. Adopting a
funding model that reflects realistic costs for conducting
a multidisciplinary assessment and that is responsive to
rates of referral could allow services to develop their ideal
team, rather than make do with what they can afford.
With growing capacity issues being identified internation-
ally, this might also enable teams to respond to growing
demand while achieving the timeliness and comprehen-
sive assessment required by NICE.3 16 commissioners and families. This might also help to address concerns
identified in a recent survey of over 1000 parents around
their negative experiences of the diagnostic process and
indeed post-diagnostic support.17
While additional funding required to adequately
address diagnostic costs may be significant, it is evident
that longer term costs to society are more challenging.
Early diagnosis and intervention can help, enabling those
caring for children to understand and better manage
difficulties.18–20 Investing in high-quality initial assess-
ment and support are likely to be offset by long-term
 savings that could include a reduction in widespread
financial impact on families, including reduced employ-
ment, and bankruptcy.21–23
A number of studies modelled potential savings made
by effective early interventions24–26 giving projected
lifetime individual savings of €1.1 million30 or $187 000
to $203 000 per child between the ages of 3 and 22
years old.24 Annual US costs have been estimated at
$126 billion,25 while in the UK, annual costs of supporting
childhood autism is estimated to be approximately
£2.7 billion27 and estimated £25 billion for adults.27 28
NICE suggests the mean annual total cost per child or
young person with autism in the UK is £25 400.29 In child-
hood, the greatest financial burden falls on families and
education, whereas in adults the main contributors are
supportive living accommodation and individual productivity loss.30

CONCLUSIONS
The assessment required to explore possible diagnosis of
ASD is complex, ideally demanding the involvement of
a multidisciplinary team. This study suggests this typi-
cally takes 13 hours of professional time. Based on UK
costings, this costs around £650–1000 ($975–$1500)
per child. As this reflects practice based in part on available
resources, consideration should be given to basing
costs on the NICE exemplars3 rather than who is available
locally. Additional resources should be included for
intervention, investigation, management of comorbid
conditions and ongoing support that would need multi-
agency approaches including education and social care.

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Brighton and Sussex Medical School and led the writing up of the final paper. MG
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worked as an accountant before studying medicine. AG brought the perspective
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REFERENCES
1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Fifth Edition. VA: Arlington American Psychiatric Association, 2013.
2. World Health Organization. International classification of diseases. Geneva: World Health Organization, 1992.
3. B. British Association of Community Child Health and Royal College of Paediatrics and Child Health: Covering all bases. Community child health: a paediatric workforce guide. Geneva: World Health Organization, 1992.
4. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Fourth Edition. Washington DC: American Psychiatric Association, 1994.
5. WHO. The ICD-10 classification of mental and behavioural disorders. Clinical descriptions and diagnostic guidelines. Tenth edition. Geneva: World Health Organization, 1992.
6. B. British Association of Community Child Health and Royal College of Paediatrics and Child Health: Covering all bases. Community child health: a paediatric workforce guide. London, UK: RCPCH, 2017.
7. Lord C, Rutter M, Le Couteur A. Autism diagnostic interview-revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. J Autism Dev Disord 1994;24:659–85.
8. Lord C, Rutter M, Goode S, et al. Autism diagnostic observation schedule: a standardized observation of communicative and social behavior. J Autism Dev Disord 1989;19:185–212.
9. National Institute for Health and Care Excellence. Evidence update 40: autism diagnosis in children and young people. Manchester, UK: National Institute for Health and Care Excellence, 2013.
10. American Academy of Neurology. Practice parameter: screening and diagnosis of autism. St Paul, MN: AAN Quality Standards Subcommittee, 2000.
11. Johnson CP, Myers SM. American Academy of Pediatrics Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. Pediatrics 2007;120:1183–215.
12. Taylor L, Brown P, Eapen V, et al. Autism spectrum disorder diagnosis in Australia: are we meeting best practice standards? Brisbane, Aus: Autism Co-operative Research Centre, 2016.
13. Monitor and NHS England. Towards an NHS payment system that does more for patients. http://www.monitor.gov.uk/regulating-health-care-providers-commissioners/regulating-prices-nhs-funded-care/towards-nhs-payment-system-does-more-patients (accessed 7 Jan 2014).
14. Curtis L, ed. Unit costs of health and social care 2013. Canterbury, UK: Personal Social Services Research Unit, University of Kent, 2013.
15. Weiss LA, Shen Y, Korn JM, et al. Association between microdeletion and microduplication at 16p11.2 and autism. N Engl J Med 2008;358:667–75.
16. National Institute for Health and Care Excellence. Q51 Autism quality standard. Manchester, UK: National Institute for Health and Care Excellence, 2014.
17. Crane L, Chester JW, Goddard L, et al. Experiences of autism diagnosis: a survey of over 1000 parents in the United Kingdom. Autism 2016;20:153–62.
18. Diggle T, McConachie HR, Randle VR. Parent-mediated early intervention for young children with autism spectrum disorder. Cochrane Database Syst Rev 2003;1:CD003496.
19. Farmer J, Reupert A. Understanding autism and understanding my child with autism: an evaluation of a group parent education program in rural Australia. Aust J Rural Health 2013;21:20–7.
20. Gura GF, Champagne MT, Blood-Siegfried JE. Autism spectrum disorder screening in primary care. J Dev Behav Pediatr 2011;32:48–51.
21. Sharpe DL, Baker DL. Financial issues associated with having a child with Autism. J Fam Econ Issues 2007;28:247–64.
22. Cidav Z, Marcus SC, Mandell DS. Implications of childhood autism for parental employment and earnings. Pediatrics 2012;129:617–23.
23. Lavelle TA, Weinstein MC, Newhouse JP, et al. Economic burden of childhood autism spectrum disorders. Pediatrics 2014;133:e52 0–e529.
24. Jacobson JW, Mulick JA, Green G. Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case. Behav Interv 1998;13:201–26.
25. Mandell DS. Understanding and addressing the impact of autism on family. LDI Issue Brief 2012;17:1–4.
26. Peters-Scheffer N, Didden R, Korzilius H, et al. Cost comparison of early intensive behavioral intervention and treatment as usual for children with autism spectrum disorder in The Netherlands. Res Dev Disabil 2012;33:1763–72.
27. Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. Autism 2009;13:317–36.
28. Reed P, Osborne LA. Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders. Arch Dis Child 2012;97:927, 31.
29. National Institute for Health and Care Excellence. CG170 Autism - management of autism in children and young people: costing statement. Manchester, UK: National Institute for Health and Care Excellence, 2013.
30. Buescher AV, Cidav Z, Knapp M, et al. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatr 2014;168:721–8.