

A national research survey of childhood autism assessment services in the UK: empirical evidence of diagnostic practice, challenges and improvement opportunities

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ABSTRACT

Background The UK National Health Service (NHS) Long Term Plan aims to reduce waiting times for childhood autism diagnostic assessment and improve parent and child satisfaction. This empirical research investigated current childhood diagnostic practice provision, and changes made by teams to address challenges faced.

Methods Data were collected using an online semi-structured research questionnaire. UK childhood autism diagnostic assessment services (for children aged 1–18 years) were invited to participate through multidisciplinary clinical networks, special interest groups and professionals mailing lists. The study was on the National Institute for Health Research Clinical Research Network portfolio.

Results 128 clinicians from diverse NHS services responded including: 10 (8%) integrated services, 46 (36%) Child and Adolescent Mental Health Services (CAMHS) and 72 (56%) paediatric services. A minority of services (23, 17.9%) reported always meeting the National Institute for Health and Care Excellence guidance for assessment. Referrals rose 115% between 2015 and 2019. Clinicians described increased child and family complexity compared with previously; children had more co-occurring physical, mental health and neurodevelopmental conditions and there were more frequent family health problems and safeguarding concerns. Most services (97, 75.8%) reported recent funding stayed constant/decreased. Incomplete multidisciplinary teams (MDTs) were frequently reported; a minority of services reported increased availability of professionals, and some experienced reductions in key professionals. Many teams were unable to undertake assessments or make recommendations for associated neurodevelopmental and co-existing conditions. Teams described improvement strategies implemented (eg, adapting professionals' roles, supporting parents).

Conclusions Most UK autism paediatric and CAMHS diagnostic teams experience significant challenges affecting the assessment of children with possible autism, and recommendations regarding treatment/intervention. Where CAMHS or paediatric services work in isolation, there are often competency gaps in MDTs and ability to deliver full neurodevelopmental and mental health assessments. Teams identified service improvement strategies; however,

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Waiting times for childhood autism diagnostic assessments are longer than recommended in UK national guidance causing parent and child dissatisfaction.

WHAT THIS STUDY ADDS

⇒ UK autism teams reported increasing numbers of referrals and assessments, increased child and family complexity as well as a rise in co-occurring physical, mental health and neurodevelopmental conditions.
⇒ Safeguarding concerns were more commonly reported than before.
⇒ Additionally, many teams were unable to meet the National Institute for Health and Care Excellence (NICE) guidance.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The study findings highlight that the Child and Adolescent Mental Health Services and paediatric services completing childhood autism assessment and diagnosis work independently of each other.
⇒ This means that their multidisciplinary teams (MDTs) commonly lack the resources and capacity to deliver high-quality and thorough NICE-compliant autism assessments.
⇒ The study identified opportunities that have been used to change provision, addressing challenges faced by diagnostic teams, for example, to improve the timeliness and validity of childhood autism diagnostic assessments.
⇒ Some of the innovative practices described can be used to support clinical service developments required to enable teams to meet recent UK guidance and similar international initiatives.
⇒ The findings are relevant to international policy-makers, clinicians and parents, and can inform future development of childhood autism diagnostic services and clinical guidance recommendations.

investment in MDT expertise is required to enable services to implement changes to meet the needs of children and families.

INTRODUCTION

UK National Health Service waiting times for childhood autism diagnostic assessments in paediatric and Child and Adolescent Mental Health Services (CAMHS) are longer than recommended in national guidance.^{1–3} This is a cause of parent and child dissatisfaction.⁴ International studies from New Zealand, Canada and the USA describe similar challenges accessing diagnostic assessment and interventions for co-existing conditions, alongside insufficient parent support.^{5–11}

Timely diagnosis reduces parent stress and facilitates understanding a child's strengths and difficulties and accessing appropriate ongoing support.¹² The UK NHS Long Term Plan (2019) aims to reduce waiting times³; however, few models of practice describe how to accomplish this.¹³ In Scotland, a new diagnostic pathway led to reduced waiting lists in one health board.¹⁴ Other potential international solutions include pre-appointment information gathering,¹⁵ single practitioner assessments,^{16 17} holistic profiling¹⁸ and better coordination of health and education pathways.¹⁹ Increased joint working between paediatric and CAMHS professionals/teams facilitates efficient and holistic assessments, for example, avoiding repeat assessments for children with suspected autism and attention deficit hyperactivity disorder (ADHD),²⁰ which is important as co-existing conditions are common in children with autism.^{21 22}

The UK National Institute for Health and Care Excellence (NICE) publishes clinical guidance (CG) and quality standard (QS) recommendations for evidence-based best practice for recognition, referral and diagnosis of autism spectrum disorder in children (CG128 and QS51).^{1 2} NICE CG and QS recommend an MDT assessment, use of structured assessments and that teams have the competencies to assess neurodevelopmental, physical and mental health conditions in children undergoing autism diagnostic assessment.^{1 2}

This study is one component of a UK national programme of research: A Realist Evaluation of Autism Service Delivery (RE-AScED). The programme comprised (i) a literature review¹³; (ii) the survey of UK autism diagnostic team clinicians and (iii) in-depth case studies involving interviews with children, families and practitioners.²³ We report here the findings from the national survey of paediatric and CAMHS teams on challenges faced by services, and compare service provision, challenges faced and solutions used. The survey aimed to identify: (i) barriers to provision of timely and valid autism assessment and diagnosis services, (ii) variations in assessment and diagnostic service provision across paediatric and CAMHS settings and (iii) adaptations to provision that have been made to improve services.

METHOD

Data collection was by cross-sectional online survey. There is no central professional or NHS organisational record of numbers of UK autism diagnostic teams and snowball sampling facilitated participant recruitment. UK childhood autism diagnostic assessment services (for children aged 1–18 years) were invited to participate through the British Academy of Childhood Disability, British Association of Community Child Health, Royal College of Psychiatrists, multidisciplinary clinical networks, special interest groups and professionals mailing lists for those working in childhood autism assessment and diagnosis teams (June–November 2020). Reminders were sent via teams; teams were encouraged to contact other teams they knew and let them know about the study; the Clinical Research Network supported recruitment. One multidisciplinary clinician from each service completed the survey.

The non-validated survey questionnaire was semi-structured with open/closed response options. Part 1 covered (i) service setting (16 questions); (ii) diagnostic service and NICE guidance (3 questions); (iii) referral/pre-assessment (4 questions); diagnostic assessment and conclusions (15 questions) and (v) recommendations (1 question). Part 2 comprised 10 questions on adaptations services had made, or would like to make to address challenges; participants were encouraged to report effectiveness of adaptations.

The survey was distributed and completed online using survey software (Qualtrics). Participants accessed the survey link on completion of informed consent. Reminder emails were sent to maximise response.

Data were analysed using descriptive statistics. Pearson's χ^2 test of difference were used to analyse categorical responses.²⁴ Open-text survey responses used content analysis, which involved familiarisation with data, preliminary identification of codes and developing a coding frame. A section of data was coded to inform development and refining of the coding frame during an iterative process prior to coding the whole dataset.²⁵ Inter-rater reliability was assessed for 10% of the data with an agreement threshold ($\geq 80\%$).

Patient and public involvement and engagement

The survey was developed by parents, clinicians and academic partners (online supplemental appendix 1). Parents and representatives from parent support organisations co-designed the funding application and study methods.

RESULTS

Responses were received from 128 UK NHS teams including 46 CAMHS (36%), 72 paediatric services (56%) and 10 integrated services (8%); 113 (88%) responses were from teams in England, 9 in Scotland, 4 in Northern Ireland and 2 in Wales. Eighty-four services covered mixed urban/rural areas (65.6%); 36 urban (28.1%) and 8 rural (6.3%). Limited results from the

Table 1 Number of children referred to and assessed by teams between 2015 and 2019

Year	Referred to the pathway: median (range)		Assessed through the pathway: median (range)	
	N*		N*	
2019	78	257 (6–2060)	77	200 (5–1293)
2018	56	209 (2–1688)	60	179 (11–1098)
2017	47	200 (33–1506)	47	151 (18–1173)
2016	37	200 (40–1208)	39	129 (32–977)
2015	33	96 (43–993)	35	113 (27–720)

*Number of teams who had access to data.

10 integrated services are presented due to the small number of responders.

As expected, the age range of children seen varied between services. All paediatric teams assessed children aged ≤ 4 years (72, 100%). Sixteen paediatric teams (22.2%) assessed children aged 0–8 years, and 56 teams (77.7%) assessed children up to age 18 years. Almost all CAMHS teams assessed young people aged 8–18 years (45, 97.8%). Twenty-two CAMHS teams (47.8%) saw children aged ≤ 4 years and 24 (52.1%) assessed children aged 5–7 years.

Referrals and assessments

Table 1 clearly shows substantial increases in the median number of children referred to and assessed through autism diagnostic pathways each year from 2015 to 2019. Thirty-one teams reported data from 2015 and 2019, with referrals rising from 140 in 2015 to 301 in 2019 (a 115% increase). The number of completed assessments reported by 34 teams rose from 119 to 200 over the same period (a 68% increase). Paediatric and CAMHS teams' estimates showed no difference in the proportion assessed and given autism diagnoses (76% paediatrics, 75% CAMHS). 2019/20 waiting times to first assessment for children referred to paediatrics and CAMHS was similar (9 months, $n=61$ and 10 months, $n=42$, respectively). Based on the available data (26 teams), there was no evidence of an increase in waiting times between 2017 and 2019.

Prediagnostic assessment information collected

Twenty-eight (38.9%) paediatric and 34 (73.9%) CAMHS teams used screening measures for co-occurring conditions. More than 80% of teams collected reports from other professionals who knew the child. Only 19 (26.4%) paediatric and 19 (41.3%) CAMHS teams gathered reports from others who knew the child (eg, teachers, sports coaches) (online supplemental table S1). Most services thought collecting pre-assessment information was useful (117, 91.4%), as it improved assessment speed (89, 69.5%), quality (109, 85.2%) and satisfaction (101, 78.9%) with the assessment, and aided in the identification of co-existing conditions (100, 78.9%).

Meeting NICE guidance

Only a minority of teams (23, 17.9%) reported always being able to meet NICE diagnostic assessment guidance; 86 (67.2%) teams reported that it was possible to meet NICE guidance most of the time or always (table 2). Some teams rarely or never met individual NICE QS, for example, providing a key worker to coordinate the care and support detailed in personalised plans (paediatrics, 59.8%; CAMHS 32.6%). Only half of teams always assessed children with autism and behaviours that challenge for possible triggers, including physical and mental health conditions and environmental factors. One-third of teams rarely or never offered families a discussion about psychosocial interventions (paediatrics, 37.5%; CAMHS 23.9%).

Diagnostic assessment and conclusions

Most paediatric and CAMHS assessment services had a defined multidisciplinary team (MDT) (105; 88.9%); however, MDT composition differed significantly between paediatric and CAMHS teams (table 3). As expected, paediatric core teams were more likely than CAMHS to have a paediatrician (70 vs 11: χ^2 (3) = 60.25, $p=0.000$) and a speech and language therapist (62 vs 21: χ^2 (2) = 14.009, $p=0.001$). Core CAMHS teams were more likely than paediatrics to have a psychologist (40 vs 32: χ^2 (2) = 9.357, $p=0.009$), assistant psychologist (28 vs 8: χ^2 (3) = 15.69, $p=0.001$) and a psychiatrist (31 vs 7: χ^2 (3) = 20.43, $p=0.000$). Only two-thirds of CAMHS teams included a psychiatrist in the core team (67.4%). A minority of teams had occupational therapists (21 paediatrics vs 16 CAMHS teams: χ^2 (2) = 0.832, $p=0.66$).

While a minority of services reported an increase in available professionals over the last 5 years, the number of professionals in most teams remained unchanged (table 3). Surprisingly, some teams experienced a reduction in key professionals. Most paediatric and CAMHS teams had no representation from a person with lived experience of autism (76.3% vs 56.5%, respectively).

There was considerable variation in assessment methods used, and the use of standardised measures/tools (online supplemental tables S2–3). Few teams used standardised autism history taking tools (38.8% paediatrics vs 58.6% CAMHS); most teams had access to use of the Autism Diagnostic Observational Schedule where needed (fewer in paediatrics than CAMHS). There was a striking between-service difference in the proportion of children receiving physical examinations, or investigations (paediatrics: 41, 56.9%; CAMHS: 5, 10.9%: χ^2 (2) = 24.90, $p=0.001$). Most CAMHS (39, 84.7%) reported not undertaking physical investigations such as genetic screening with many or most of the children.

A third of teams (46, 35.9%) reported greater complexity associated with the children/young people requiring assessment compared with 5 years ago. Complexity was defined as additional characteristics that practitioners needed to consider during autism assessment and diagnosis, including the presence of co-occurring physical,

Table 2 Meeting NICE guidance and quality standard

	Paediatrics (n=72)		CAMHS (n=46)		Integrated (n=10)		MV
Assessments always meet NICE guidance	9	12.5%	10	21.7%	4	40.0%	3
Mostly meet NICE guidance	32	44.4%	26	56.5%	5	50.0%	
Around half meet NICE guidance	6	8.3%	2	4.3%	1	10.0%	
Less than half meet NICE guidance	11	15.3%	2	4.3%	0	–	
Rarely meet NICE guidance	10	13.9%	4	8.7%	0	–	
Never meet NICE guidance	2	2.8%	1	2.2%	0	–	
Responses about teams' ability to meet the NICE QS							
a. Children or young people with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.	Always	19	26.4%	16	34.8%	2	20.0%
	Sometimes	29	40.3%	11	23.9%	5	50.0%
	Rarely	17	23.6%	15	32.6%	2	20.0%
	Never	7	9.7%	4	8.7%	1	10.0%
b. Children having a diagnostic assessment for autism are also assessed for co-existing physical health conditions and mental health problems.	Always	53	73.6%	26	56.5%	7	70.0%
	Sometimes	17	23.6%	19	41.3%	2	20.0%
	Rarely	2	2.8%	0	0.0%	0	–
	Never	0	0.0%	1	2.2%	1	10.0%
c. Families have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.	Always	31	43.1%	23	50.0%	8	80.0%
	Sometimes	22	30.6%	14	30.4%	0	–
	Rarely	12	16.7%	4	8.7%	0	–
	Never	4	5.6%	5	10.9%	2	20.0%
d. Families are offered a named key worker to coordinate the care and support detailed in their personalised plan.	Always	13	18.1%	22	47.8%	5	50.0%
	Sometimes	15	20.8%	8	17.4%	2	20.0%
	Rarely	21	29.2%	4	8.7%	0	–
	Never	22	30.6%	11	23.9%	3	30.0%
e. Families have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.	Always	28	38.9%	20	43.5%	7	70.0%
	Sometimes	16	22.2%	13	28.3%	1	10.0%
	Rarely	14	19.4%	6	13.0%	0	–
	Never	13	18.1%	5	10.9%	2	20.0%
f. Children with autism are not prescribed medication to address the core features of autism.	Agree	71	98.6%	42	91.3%	10	10.0%
	Disagree	1	1.4%	4	8.7%	0	–

Continued

Table 2 Continued

	Paediatrics (n=72)	CAMHS (n=46)	Integrated (n=10)	MV				
g. Children with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.	Always	29	40.3%	23	50.0%	7	70.0%	2
	Sometimes	34	47.2%	23	50.0%	1	10.0%	
	Rarely	5	6.9%	0	0.0%	2	20.0%	
	Never	2	2.8%	0	0.0%	0	–	
h. Children with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.	Agree	69	95.8%	43	93.5%	8	80.0%	1
	Disagree	3	4.2%	2	4.3%	2	20.0%	
CAMHS, Child and Adolescent Mental Health Service; MV, missing value; NICE, National Institute for Health and Care Excellence; QS, quality standard.								

Table 3 Professional disciplines who are members of the autism spectrum diagnostic assessment team; and whether over the last 5 years the amount of these professionals' time in the team increased, decreased or stayed the same

	Core team		Not in core team but available if needed						CAMHS (n=46)						MV						
	Paediatrics (n=72)		CAMHS (n=46)		Paediatrics (n=72)		CAMHS (n=46)		Paediatrics (n=72)		CAMHS (n=46)		Stayed the same		Stayed the same						
Paediatrician	70	97.2%	11	23.9%	2	2.8%	20	43.5%	26	36.1%	11	15.3%	32	44.4%	6	13.0%	21	45.7%	6	13.0%	17
Psychiatrist	7	9.7%	31	67.4%	28	38.9%	13	28.3%	5	6.9%	10	13.9%	10	13.9%	10	21.7%	20	43.5%	10	21.7%	43
Psychologist	32	44.4%	40	87.0%	18	25.0%	5	10.9%	22	30.6%	15	20.8%	13	18.1%	11	23.9%	14	30.4%	11	23.9%	23
Speech and language therapist	62	86.1%	21	45.7%	8	11.1%	15	32.6%	28	38.9%	15	20.8%	25	34.7%	9	19.6%	11	23.9%	9	19.6%	12
Occupational therapist	21	29.2%	16	34.8%	26	36.1%	16	34.8%	11	15.3%	4	5.6%	7	9.7%	5	10.9%	16	34.8%	5	10.9%	39
Assistant clinical psychologist	8	11.1%	28	60.9%	23	31.9%	10	21.7%	13	18.1%	7	9.7%	22	30.6%	4	8.7%	15	32.6%	4	8.7%	51
Nursery nurse	9	12.5%	1	2.2%	10	13.9%	14	30.4%	18	25.0%	2	2.8%	6	8.3%	4	8.7%	10	21.7%	4	8.7%	93
Educational professionals	19	26.4%	8	17.4%	24	33.3%	17	37.0%	11	15.3%	10	13.9%	13	18.1%	2	4.3%	16	34.8%	2	4.3%	54
Specialist nurse	20	27.8%	31	67.4%	12	16.7%	6	13.0%	8	11.1%	2	2.8%	11	15.3%	2	4.3%	17	37.0%	2	4.3%	53
CAMHS, Child and Adolescent Mental Health Service; MV, missing value.																					

mental health and neurodevelopmental conditions, safeguarding concerns, family health problems, disagreements between health professionals and parents or children being home schooled. Complexity had increased in many specific areas including the possible presence of one or more neurodevelopmental disorders (89, 69.5%), suspected or diagnosed mental health condition(s) (84, 65.6%) and discussion of pathological demand avoidance (68, 53.1%) (online supplemental table S4).

There were significant differences between services in assessing for, diagnosing or making recommendations for neurodevelopmental and co-existing conditions (table 4). In many areas, the ability to make diagnoses and recommendations followed MDT expertise and clinical setting, for example, paediatric teams were more likely to make diagnoses and recommendations around disordered development, developmental language disorder and developmental coordination disorder; and CAMHS teams were more likely to complete assessments and recommendations for intellectual/learning disability, ADHD and mental health conditions. Many teams needed to make onward referrals for assessments.

Despite increase in demand, only 38 teams (32.2%) reported service funding had increased over the past 5 years while most reported funding stayed constant (63, 53.4%) or decreased (17, 14.4%).

Adaptations to improve services

Teams reported adaptations within current resources to address challenges, and to improve diagnostic assessment and identification of co-existing conditions (online supplemental table S5). Ninety teams (70.3%) had improved ways to obtain good quality information at referral, for example, questionnaires from parents or education settings. Fifty-eight teams (43.9%) had introduced use of digital technology, that is, computerised systems/software. Participants reported the effectiveness of adaptations (online supplemental table S6), describing benefits from increasing support for families, broadening assessment disciplines/skill mix, a single pathway to consider autism spectrum disorder and ADHD and reducing the amount of assessment if there is sufficient evidence for earlier diagnosis and recommendations.

Teams most frequently commented that with additional resources (table 5), they would increase specialist MDT expertise (paediatrics: 60, 83%; CAMHS: 21, 45.7%); and provide more support before, during and after assessment (paediatrics: 29, 40.2%; CAMHS: 23, 50%). A third of teams thought increased resources could reduce waiting lists and improve timeliness (paediatrics: 27, 37.5%; CAMHS: 15; 32.6%). A quarter of teams would expand their team and capacity to complete more assessments (larger premises, increased professional time) (paediatrics: 17, 23.6%; CAMHS: 12, 26.1%). Teams would also increase joint working (paediatrics: 12, 16.7%) and conduct more holistic assessments including for co-existing conditions (CAMHS: 9, 19.6%).

DISCUSSION

This large empirical study explored delivery of UK childhood autism assessment and diagnostic services. The study adds substantially to previous research by reporting for the first-time data on services' compliance with NICE guidance and comparing paediatric and CAMHS teams on service provision and challenges faced. The study gathered data on the characteristics of contemporary UK childhood autism diagnostic assessment services, including access to resources and expertise, numbers of children referred and what clinical services and practitioners are able to offer children and families. The study shows high variability between services, on key characteristics that lead to good practice.

Teams reported substantially increased referrals and assessments each year since 2015, greater complexity of children and families, gaps in MDT professionals and expertise and most had received no increase in funding. In combination, this meant most teams were unable to complete autism assessments in a timely manner, many were unable to offer assessments in accordance with NICE guidance and most were unable to complete additional assessments associated with neurodevelopmental and co-existing conditions commonly seen with autism.^{8 21}

Research suggests gathering pre-appointment information is one solution to improve diagnostic processes, speed up assessment and reduce waiting lists.¹⁵ While fewer than half of teams said they completed school or home visits, our findings show teams gathered information using a wide range of other methods, for example, referral templates, written reports from educational professionals, information from organisations set up to support children on the waiting list. Teams viewed collection of pre-appointment information as beneficial to the assessment process, improving quality and satisfaction.

Despite some teams being mostly or always NICE compliant, most teams struggled to conduct assessments that fully met NICE guidance recommendations and QS. Previous research highlights international variability in guidance recommendations for childhood autism diagnostic assessment, including whether an MDT assessment is required in all cases.²⁶ Some have suggested 'front-loading' expertise²⁷ with a single professional assessment, progressing to a consensus diagnostic evaluation for complex cases.¹⁷ Overall fewer than 40% of teams in our study said it was possible to meet UK NICE CG all the time. Our findings showed teams' ability to meet NICE guidance and QS varied depending on which clinical pathway children accessed their autism assessment. For example, NICE guidance recommends assessing children for co-existing physical and mental health conditions, however, paediatrics core teams had limited access to psychiatrists, and CAMHS core teams had limited access to paediatricians. This can contribute to inequity in service provision and barriers to accessing assessments and diagnoses for co-occurring health conditions. For example, anxiety commonly co-occurs with autism,⁸ but we found that most paediatrics teams were unable to

Table 4 Teams' ability to (i) assess and diagnose other conditions and (ii) make initial recommendations about how to manage autism characteristics and/or address/treat other neurodevelopmental diagnoses or co-existing conditions

Teams able to make these diagnoses							Teams able to make recommendations for this condition								
Paediatrics (n=72)				CAMHS (n=46)			Paediatrics (n=72)				CAMHS (n=46)				
Yes	No/or we refer onwards	Yes	MV	No/or we refer onwards	Yes	MV	Yes	No/or we refer onwards	Yes	No/or we refer onwards	Yes	No/or we refer onwards	MV		
64	88.9%	7	9.7%	20	43.5%	22	47.8%	59	81.9%	11	15.3%	28	60.9%	11	23.9%
Developmental delay/disordered development															
33	45.8%	35	48.6%	34	73.9%	4	8.7%	42	58.3%	25	34.7%	31	67.4%	8	17.4%
48	66.7%	21	29.2%	12	26.1%	32	69.6%	50	69.4%	18	25.0%	16	34.8%	24	52.2%
Developmental language disorder (previously specific language disorder)															
46	63.9%	25	34.7%	3	6.5%	42	91.3%	42	58.3%	26	36.1%	8	17.4%	32	69.6%
Developmental coordination disorder															
42	58.3%	26	36.1%	1	2.2%	44	95.7%	37	51.4%	26	36.1%	3	6.5%	38	82.6%
39	54.2%	32	44.4%	38	82.6%	7	15.2%	39	54.2%	30	41.7%	38	82.6%	6	13.0%
Attention deficit hyperactivity disorder															
10	13.9%	54	75.0%	37	80.4%	8	17.4%	18	25.0%	46	63.9%	38	82.6%	5	10.9%
8	11.1%	57	79.2%	36	78.3%	8	17.4%	11	15.3%	54	75.0%	38	82.6%	5	10.9%
32	44.4%	27	37.5%	41	89.1%	5	10.9%	37	51.4%	26	36.1%	40	87.0%	4	8.7%
Recognising emotions and responding appropriately															
58	80.6%	13	18.1%	33	71.7%	12	26.1%	58	80.6%	10	13.9%	35	76.1%	7	15.2%
44	61.1%	23	31.9%	28	60.9%	17	37.0%	49	68.1%	16	22.2%	31	67.4%	11	23.9%
51	70.8%	18	25.0%	14	30.4%	30	65.2%	51	70.8%	14	19.4%	22	47.8%	19	41.3%
20	27.8%	43	59.7%	17	37.0%	26	56.5%	21	29.2%	39	54.2%	22	47.8%	20	43.5%
Pathological demand avoidance															
20	27.8%	48	66.7%	36	78.3%	9	13.0%	21	29.2%	43	59.7%	35	76.1%	7	15.2%
17	23.6%	47	65.3%	39	84.8%	6	21.7%	15	20.8%	46	63.9%	36	78.3%	7	15.2%
Assessment of risk regarding self-harm/suicidality															
36	50.0%	27	37.5%	32	69.6%	10	19.6%	28	38.9%	33	45.8%	33	71.7%	7	15.2%
44	61.1%	26	36.1%	2	4.3%	42	91.3%	40	55.6%	25	34.7%	6	13.0%	34	73.9%
Genetic conditions															
CAMHS; Child and Adolescent Mental Health Service; MV, missing value.															

Table 5 Potential improvements in diagnostic assessment services for children with possible autism spectrum disorder with increased resources

Code	Paediatrics (n=72)		CAMHS (n=46)		Illustrative quotes
	N	%	N	%	
More MDT specialist clinicians	60	83.3	24	52.1	'Access to a wider range of appropriate professionals during the assessment for example, speech and language and occupational therapy. Access to more assistant psychologists to collate relevant documents and developmental history to reduce the time required to complete the ADI-R' (CAMHS) ³⁸ 'Commission medic time to provide physical examinations when these are needed' (CAMHS) 'Inclusion of occupational therapy/psychiatry in assessment pathway' (paediatrics)
Provide more support: before, during and after diagnosis	29	40.2	23	50.0	'Workers with the role of managing those waiting; so a liaison worker to ensure they get the help they need while waiting' (CAMHS) 'Increase our postdiagnostic offer to children and families' (paediatrics)
Reduce waiting list and improve timeliness	27	37.5	15	32.6	'See people more quickly and reduce wait between stages of assessment' (CAMHS) 'Reduce waiting time from referral to assessment as well as time from first appointment to completed assessment' (paediatrics)
Expand resources and capacity	17	23.6	12	26.1	'Access to more assessment resources' (CAMHS) 'Have greater clinic room capacity so that the numbers of assessments carried out monthly can increase' (paediatrics)
More holistic approach/ better identification/ support for co-existing conditions	4	5.6	9	19.6	'More holistic assessments for example, could provide ...educational assessment for all children' (CAMHS) 'More comprehensive assessments—could include cognitive assessments...comorbidities including tics, Fetal Alcohol Syndrome' (CAMHS) 'Have a service which is able to manage the emotional and mental health issues associated with autism and to assess for trauma presentations and attachment difficulties' (paediatrics)
Increase ways of joint working	12	16.7	4	8.7	'We could do more consultations and direct joint working with community child health paediatricians' (CAMHS) 'Every child seen in a joint appointment with community paediatrics and SaLT' (paediatrics)
Improve information gathering and observation	12	16.6	3	6.5	'More observational visits' (CAMHS) 'More time for direct observations in multiple settings (including home and school)' (paediatrics)
Improve administration support and technology	5	6.9	9	19.5	'Technology to help gather and store information' (CAMHS) 'Key administrative co-ordinator who would organise all steps of the patient journey through the assessment process. Would type all letters and could act as a single point of contact for the pathway. Would coordinate all information from education etc' (paediatrics)
More training	10	13.9			'Better education of educational professionals especially early years about how to spot children and refer them early' (paediatrics) 'Offer bespoke training across the borough on gathering appropriate information and the implementation of our recommendations' (paediatrics)

ADI-R, Autism Diagnostic Interview-Revised; CAMHS, Child and Adolescent Mental Health Service; MDT, multidisciplinary team; SaLT, speech and language therapy.

diagnose or make recommendations regarding anxiety or would refer onwards. Few CAMHS teams offered assessments for co-occurring physical health conditions. Most paediatric teams were unable to make diagnoses of suicidality or self-harm. Children and families may experience further delays in the assessment and diagnosis process and reduced continuity of care when/if there are transitions between paediatrics and CAMHS services regarding co-occurring conditions. Most integrated teams were able to meet the NICE QS to offer assessments for co-existing physical and mental health problems, however, this finding may not be representative of all integrated teams given the small number recruited (n=10); most UK childhood autism assessment and diagnosis services are not currently organised in an integrated way.

Fewer than half of the teams were able to offer families opportunities to access psychosocial interventions, or provide a key worker to co-ordinate personalised

plans. Around half of the teams reported that with extra resources they would provide more support before, during and after the assessment, showing teams remain motivated to provide support and intervention for children and families.

Some professionals led services that were able to provide comprehensive services; many professionals reported frustration with their capacity to improve services, despite efforts to do so. These findings indicate that additional resources (funding, increased MDT personnel), training and improved expertise/skill mix are needed now, and in the future, to build capacity to deliver the high-quality services that professionals desire, and children and parents require. Previous studies of Child Development Teams and Autism Diagnostic services have shown the challenges faced by teams regarding MDT availability and service provision.^{28 29} This recent study highlights that many challenges persist. In accordance with previous

research,¹⁵ families continue to wait an unacceptably long time for assessment,³ which may or may not be as comprehensive as required. This causes dissatisfaction to families and clinicians.⁴ Despite this, resources have not increased for many teams and there has been a reduction for some.

The MDT in paediatrics and CAMHS broadly dictated assessments that were undertaken, and recommendations made. The challenges for CAMHS to provide required medical assessments recommended by NICE was notable. Many teams were able to offer an excellent service with each of the professionals recommended by NICE represented in their core teams. However, some clinicians reported declining or static investment, or only investment for less qualified or less expensive staff, for example, nursery nurses, while opportunities for service development and gaps in professional time in the team were evident. Previous research suggests reducing professional clinical time may improve pathway efficiency but abbreviated/fast-tracked assessments may be less holistic and fail to address co-existing conditions.^{14 16 17}

The survey findings show that teams are managing increasingly complex referrals. Previous research findings demonstrate children with complex presentations and additional diagnoses, for example, ADHD, are diagnosed later than those without.¹² Integrating paediatric and CAMHS services to deliver a neurodevelopmental pathway recognising co-occurring difficulties with social communication and hyperactivity, rather than separate pathways (autism/ADHD) may improve efficiency but there may be barriers to implementation.^{20 30–32}

Although the number of integrated services in the study was small, limiting comparisons, there was some evidence that teams were able to mostly or always meet NICE guidance; integrated services are more likely to have a broader MDT skill mix and capacity to undertake comprehensive assessments and make recommendations for support/interventions/treatments indicated.²⁰

Regarding limitations, there was limited access to older records (data from 2015 to 2019), showing continued need for improved service data collection.¹⁴ Survey data on the proportion of children referred and assessed who went on to receive a diagnosis was limited. While many responses were received, there was no information on the number of teams approached to participate and neither professional nor NHS organisations know the number of UK autism diagnostic teams. However, it seems unlikely that there was systematic bias in England; fewer responses were received from other UK countries. The survey was designed prior to the COVID-19 pandemic but conducted during 2020. This may have reduced response rates from teams and explain description of expedited adoption of digital technology solutions to facilitate socially or geographically distanced assessment.³³ Some clinicians had changed their service in an effort to improve assessments and reported the success of adaptations. Many identified adaptations cost little; however, some require investment of funds

and training (eg, digital technologies).³⁴ It was evident that innovative teams introduced a number of changes, rather than a single 'one-size-fits-all' solution. Respondents described changes they would like to make with more resources (eg, improve timeliness) and innovative approaches. The findings demonstrate the requirement for identifying flexible models of working effectively and efficiently within children's autism assessment and diagnostic services.¹⁴ The research programme built on the survey findings by conducting case studies of autism diagnostic assessment services including interviews with children and families to identify effective approaches to reduce waiting times, and deliver high-quality, comprehensive diagnostic assessments.

CONCLUSION

This is the first study to explore challenges to compliance with NICE guidance in UK childhood autism assessment and diagnosis services. The study findings highlight that CAMHS and paediatric services mostly work independently of each other to complete childhood autism assessments, and MDTs often lack the resources capacity to deliver high-quality and thorough NICE-compliant autism assessments. The study also identified opportunities for change to address challenges faced by diagnostic teams and improve timeliness and validity of childhood autism diagnostic assessments. These findings are relevant for UK and international policymakers, commissioners, clinicians and parents. Some innovative practices described are being used to support clinical service developments to meet the goals of the NHS Long Term Plan, recent guidance and similar international initiatives.^{35–37} The findings can also be used to inform service development and updates to UK NICE CG and QS for childhood autism assessment and diagnosis services and pathways.

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