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Lost opportunities for young people with ASC under early intervention: A service evaluation from a central London Forensic CAMHS service

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ABSTRACT

Background: Little is known about the needs and risk behaviours of children and young people (CYP) with Autistic Spectrum Condition (ASC) referred to Community Forensic Child and Adolescent Mental Health Services (C-FCAMHS).

Methods: A retrospective service evaluation considering all CYP (n = 444) referred to a C-FCAMHS in London from mid-2018 to December 2022. We considered demographic and family background data, comorbid diagnoses, service involvement and reasons for North West London Community Forensic Child and Adolescent Mental Health Services (NWLFCAMHS) referral and NWLFCAMHS input and risk assessment of CYP with and without ASC.

Results: At referral, close to one-quarter (22.8 %; male n=88,25.7 %; females n=8,18.9 %) of referred CYP had a diagnosis of ASC; a third of these had a co-occurring neurodevelopmental disorder. A further 25 CYP were awaiting ASC assessment, of which six CYP individuals were subsequently given an ASC diagnosis. Of the CYP with ASC, close to four-fifths were open to CAMHS (78.1 %) and social care (79.2 %) on referral. Over two-fifths (42.5 %) of CYP with ASC were referred due to violent behaviours and 59.2 % were considered at moderate risk to others. Conclusion: There are higher prevalence rates of ASC in referrals to our C-FCAMHS than in the general adolescent population, with disproportionally higher rates in girls and those from racialised backgrounds. Missed opportunities for support to reduce development of risk behaviours were noted, including insufficient individual support plans in education, social care and CAMHS. There is much need to support early identification of ASC across all demographically diverse groups to enable early support from services and prevent escalation to high-risk behaviours.

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1. Introduction

Autistic Spectrum Condition (ASC) is a lifelong neurodevelopmental condition that affects children and young people (CYP). It is a disability (The Autism Act, UK Government Legislation, 2009). Diagnostic criteria, as described in ICD-11, are based on (i) difficulties with social communication and social interaction, (ii) restricted and repetitive patterns of behaviours, interests and activities, and (iii) sensory sensitivity (O'Nions et al., 2023). ASC is a non-linear spectrum, such that challenges are experienced at different severity levels in different individuals (United States Government Accountability Office, 2016).

Since 2018, 2.94 % of 10–14 years old children (1 in 34) in the UK received an ASC diagnosis (O'Nions et al., 2023). In a 2017 UK national survey, 1.2 % of children aged between 5–19 years had ASC (Health and Social Care Information Centre, 2018). ASC was found to be more common in boys (1.9 %) than girls (0.4 %) and, along with other "less common disorders", much more common in White-British children compared to those from racialised backgrounds. There are concerns that ASC diagnoses may be missed in girls and those from racialised backgrounds (Williams, 2022).

Many CYP with ASC are unsupported; 70 % of children on the autism spectrum are receiving mainstream education, whilst the remaining number largely receive specialist provision or are being home-schooled (Department of Education, 2018). There is much concern that children and young people (CYP) with ASC are "forgotten" and "neglected" with ongoing unmet needs and limited support resulting in offending or risk behaviour (Hughes et al., 2012). Hales et al. (2022) found that in a census of CYP from England detained in secure institutions in 2016, 10 % had ASC (for 4.3 % it was their primary diagnosis and a further 6.3 % were diagnosed but not their primary need). A national evaluation of the new Community Forensic Child and Adolescent Mental Health Service (C-FCAMHS) network in England found a prevalence of ASC in CYP referred to regional C-FCAMHS services of 26.5 % (Lane et al., 2021), similar to that reported by Smith et al. (2022) for referrals to their C-FCAMHS. However, there are no studies evaluating the services' responses and needs of autistic CYP who are presenting with high-risk behaviours.

C-FCAMHS are highly specialist mental health services across England, supporting professionals and services working with CYP with risk behaviours and/or who are in contact with the Youth Justice System (YJS). They aim to support the maintenance of community and educational placements to ensure positive outcomes for the CYP and their families (Lane et al., 2021). North West London Community Forensic Child and Adolescent Mental Health Services (NWLFCAMHS) work across the 8 boroughs of the North West London Integrated Care System, covering a vastly diverse urban population.

Our study aims to analyse data collected as part of a service evaluation of our NWLFCAMHS service to investigate:

- The demographics of CYP with ASC referred to NWLFCAMHS, particularly focussing on gender and ethnicity compared to prevalence rates in the general population
- Any indication of missed diagnoses in this patient group, specifically those from racialised backgrounds and/or female gender
- Missed opportunities to support CYP with ASC prior to referral
- Input given by the NWLFCAMHS team and whether this has positive outcomes.

2. Methods

2.1. Design

This study is a retrospective observational service evaluation.

2.2. Sample

The sample consisted of all referrals to NWLFCAMHS from the start of the service (mid-2018) through to end of December 2022. Referrals are made from any professional working with CYP living in the 8 Boroughs of North West London.

2.3. Data collection

Data collection focused on: demographics (age, gender, ethnicity); family background (including placement, parental criminality, domestic violence); reasons for referrals; diagnoses (including comorbid Attention Deficit Hyperactivity Disorder (ADHD), Learning Disability (LD) and ASC); service involvement (CAMHS, Youth Offending Teams (YOT), Education, social care) and NWLFCAMHS involvement (level of input, risk assessment, discharge plans).

2.4. Ethical approval

This service evaluation of needs and input for neurodivergent CYP referred to NWLFCAMHS was part of a full local service evaluation, including data collected for the service's annual report and specific data requested by NHS England about the needs of those with neurodiversity, approved by the West London NHS Trust Audit Committee. Therefore, consent from service users was not required.

2.5. Statistical analysis

We analysed data about each CYP accessing our service, therefore a re-referral was counted as a continuation of the initial referral. For this study, we compared those with a confirmed diagnoses of ASC (ASC group) to those without any suspected or diagnosed neurodevelopmental disorders (no-NDD group). There were many CYP awaiting assessment for ASC and/or other neurodevelopmental disorders (NDD) with possible but unconfirmed ASC and/or other NDD; as many CYP who went on to have assessments were not diagnosed with NDD, including those awaiting an assessment in either the diagnosed or non-diagnosed groups could conflate the figures, and therefore, we excluded these from analyses other than comparisons of demographic characteristics (where they were considered as a separate group).

Frequencies and percentages were used to present all descriptive data with one exception, age, which was described by means and standard deviations. Comparisons involving categorical variables between different groups were made using Chi-square or Fisher's exact tests, with odds ratios (ORs) and 95 % confidence intervals (CI) calculated to describe the magnitude of (significant) pairwise differences. Comparisons of age were made with independent groups t-tests; bias and accelerated bootstrapping (2000 replications) was employed where distribution of age within groups did not approximate a Gaussian distribution. McNemar mid-p test for binary matched-pair data (Fagerland et al., 2013) was employed to compare frequencies of individuals considered to be a high risk on referral to NWLFCAMHS and then at subsequent discharge. The criterion for statistical significance was set at p < 0.05. All statistical analysis were carried out using SPSS (IBM, Version 28.0).

3. Results

From the start of the service (mid-2018) through to the end of 2022, there were 494 referrals, including 50 (10.1 %) re-referrals. Therefore, in total, 444 individual CYP were referred to NWLFCAMHS. At the end of December 2022, 413 (93.0 %) had been discharged and 31 (7.0 %) remained open. Data analyses were conducted on 443 CYP with NDD diagnostic data; 342 (cis) male, 95 (cis) female, and 6 who were non-binary, trans-male or trans-female.

3.1. CYP with ASC

One hundred and one (101, 22.8 %) CYP had a diagnosis of ASC on referral. A further 25 CYP had an ASC assessment whilst open to NWLFCAMHS, 7 by the NWLFCAMHS team and 18 by another service. Of these, 6 (24 %) were given a diagnosis of ASC (Fig. 1). One CYP had their diagnoses changed from ASC to psychosis. Therefore, at census time, the total number of CYP with a diagnosis of ASC who had been open to NWLFCAMHS was 106 (23.9 %). Thirteen of these remained open at the end of the census period.

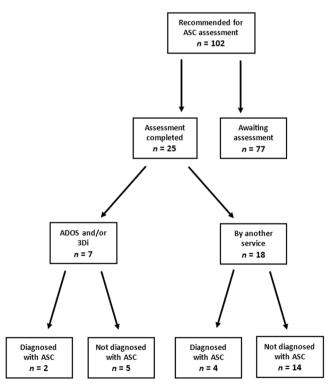


Fig. 1. Pathways for CYP open to NWLFCAMHS recommended for assessment for ASC.

This observed rate of ASC in CYP referred to NWLFCAMHS is higher than that estimated (2.57 %; OR=12.15, 95 % CI = 9.76,15.12) in children/adolescents (\leq 19 years) registered with the UK Clinical Practice Research Datalink (CPRD) primary care database (Russell et al., 2022).

3.2. Age, gender and ethnicity

The mean age of those with ASC was 14.73 (SD = 2.2) years. Most (88, 83.0 %) were male. There were no significant differences in age or gender of those with ASC and those with no-NDD (Table 1). The prevalence rate of (cis) males with ASC being referred to NWLFCAMHS was higher (88, 25.7 %) than (cis) females (18, 18.9 %). There was a trend reflecting lower rates of (cis) males with "suspected ASC" and awaiting assessment at the point of discharge than females, but the difference was not significant. Of the 25 CYP who had an assessment completed whilst open to NWLFCAMHS, almost all (23, 92.0 %) were male.

Notably, the elevated rate in our sample was not an artefact of the NWLFCAMHS sample being predominantly male, as the rate was disproportionately high (relative to overall CPRD estimates stratified by gender; Russell et al., 2022) in both, young women (1.15 %; OR=20.07, 95 % CI=12.00, 33.53) and young men (4.00 %; OR=8.32, 95 % CI=6.53, 10.61) referred to NWLFCAMHS.

Most CYP with ASC were from a White ethnic background (60, 56.6 %), with far fewer from other ethnic backgrounds (16, 15 % Black / Black British; 15, 14 % Asian / Asian British; 11, 10 % Dual Heritage; and 3, 3 % Arab / Middle Eastern). This was significantly different from those with no-NDD (p < 0.001) where there was a more even distribution between CYP of different ethnic backgrounds, though still (numerically) more from a White background (Table 1). There was a more than three-fold increase in odds that a CYP with ASC referred to NWLFCAMHS was from a White ethnic background compared to any other ethnic background (OR = 3.27, 95 % CI = 1.97, 5.42); however, there was a significant decrease in associated risk of ASC in CYP from an Arab background (OR = 0.17, 95 % CI = 0.05, 0.58). Almost 40 % of those still waiting for an assessment (30 of 78, 38.5 %) were White. Of the 25 CYP who completed an assessment whilst open to NWLFCAMHS, 9 (36.0 %) were White, 6 (24.0 %) Black, 5 (20.0 %) Asian, 2 (8.0 %) Arab and 3 (12.0 %) Dual Heritage. There were similar rates (22–24 %) of CYP from White, Black and Asian backgrounds awaiting or having completed an ASC assessment after referral to NWLFCAMHS; there were proportionally less Arab CYP (10.8 %) and more from Dual Heritage (33.3 %).

3.3. Co-occurrence with other neurodevelopmental disorders (NDD)

Of those with a diagnosis of ASC, more than a third (36, 34.0 %) had co-occurring ADHD and/or LD, 8 (7.5 %) of which had ASC, ADHD and LD (Fig. 2). For those individuals with a confirmed diagnosis of ASC, there was a significant associated risk of having a diagnosis of LD compared to those without ASC (17.0 % versus 7.7 %, p = 0.009, OR=2.44, 95 % CI=1.24, 4.84). Another 78 (17.6 %) CYP were awaiting ASC assessment and 81 (18 %) had been given a diagnosis of or awaiting assessment for another neuro-developmental disorder (LD and/or ADHD). Hence there were 178 (40.2 %) with no diagnosed or suspected NDD (known as the 'no-NDD' group).

3.4. Family characteristics

At the time of referral, most CYP with ASC were living with their family (85, 80.2 %), a significantly higher proportion than CYP with no-NDD (109, 62.3 %; p = 0.002; OR=2.45, 95 % CI=1.39, 4.32; Table 2). Whilst experience of domestic violence (29, 27.4 %) and parental criminality (13, 12.3 %) were not significantly different in those with ASC from those with no-NDD, significantly less CYP with ASC experienced trauma than those with no-NDD (50, 47.2 % vs 126, 72 %; p < 0.001; OR 0.35, 95 % CI=0.21, 0.58).

Table 1

Demographic characteristics according to ASC diagnostic status. Percentage values represent proportions of sociodemographic classifications (e.g. female gender, Black/Black British ethnic background).

| | ASC (n = 106) | No NDD (n = 178) | Awaiting ASC assessment ($n = 78$) | ASC vs No NDD | ASC vs Awaiting ASC assessment |
|------------------------------|---------------------------|---------------------------|--------------------------------------|------------------|-----------------------------------|
| Age (years) | Mean (SD) 14.73 (2.20) | Mean (SD) 15.07 (1.91) | Mean (SD) 13.63 (2.88) | p 0.171 | p 0.006 |
| rige (Jellis) | n (%) | n (%) | n (%) | p | p |
| Gender | | | | 1 | ı |
| Female (cis; $n = 95$) | 18 (18.9) | 35 (36.8) | 22 (23.2) | 0.531 | 0.055 |
| Male (cis; $n = 342$) | 88 (25.7) | 140 (40.9) | 54 (15.8) | | |
| Ethnic background | | | | | |
| White (n = 177) | 60 (33.9) | 51 (28.8) | 30 (16.9) | | |
| Black/Black British (n = 96) | 16 (16.7) | 44 (45.8) | 15 (15.6) | | |
| Asian/Asian British (n = 61) | 15 (24.6) | 31 (50.8) | 10 (16.4) | | |
| Arab/Middle Eastern (n = 37) | 3 (8.1) | 26 (70.3) | 2 (5.4) | | |
| Dual Heritage (n = 66) | 11 (16.7) | 25 (37.9) | 19 (28.8) | < 0.001 | 0.062 |

Note. The No-NDD group included three young people identifying as either nonbinary, trans male or trans female, and the Awaiting ASC assessment group included two young people identifying as either a nonbinary, trans male or a trans female. Ethnic background data was not available for 4 young people (1 in ASC, 1 in No-NDD, and 2 in Awaiting ASC assessment) – percentages were calculated from available data only.

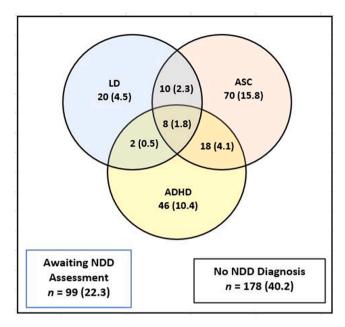


Fig. 2. Co-occurrence of LD, ASC and ADHD in CYP referred to NWLFCAMHS (n = 443) considering NDD diagnosis at discharge plus open cases at referral. Values represent frequencies (percentages).

3.5. Community services input on referral

Close to four-fifths (82, 78.1 %) of CYP with ASC were open to CAMHS on referral, significantly more than those with no-NDD (88, 49.7 %; p < 0.001); there was a more than threefold increase in odds of CAMHS involvement (OR=3.61, 95 % CI=2.08, 6.25). A similar proportion of CYP with ASC (84, 79.2 %) and CYP with no-NDD (141, 79.7 %, p = 0.933) were receiving social care input on referral. There were significantly fewer CYP with ASC open to the YOT (8, 7.5 %) than those with no-NDD (53, 29.8 %; p < 0.001,

Table 2
Family characteristics, social service involvement and educational and NEET status in CYP diagnosed with ASC and CYP with No-NDD.

| | ASC (n = 106) | No NDD (n = 178) | ASC vs No NDD |
|-------------------------------------|---------------|---------------------|------------------|
| | n (%) | n (%) | p |
| Family situation (on entry) | | | |
| Family structure | | | |
| Two parents | 41 (38.7) | 44 (25.3) | |
| One parent (with/out step-parent) | 46 (43.4) | 84 (48.3) | |
| Parent separated and both involved | 8 (7.5) | 18 (10.3) | |
| Other family/No contact with family | 11 (10.4) | 28 (16.1) | 0.097 |
| Placed with family home on referral | 85 (80.2) | 109 (62.3) | 0.002 |
| Domestic violence in family | 29 (27.4) | 66 (37.1) | 0.093 |
| Parental criminality | 13 (12.3) | 19 (10.7) | 0.694 |
| Trauma reported | 50 (47.2) | 126 (72.0) | < 0.001 |
| Education | | | |
| EHCP in Place (on entry) | 68 (64.2) | 16 (9.0) | < 0.001 |
| Type of education (during FCAMHS) | | | |
| Mainstream | 34 (32.1) | 78 (45.6) | |
| Special | 57 (53.8) | 46 (26.9) | |
| NEET | 15 (14.2) | 47 (27.5) | < 0.001 |
| Service involvement (on entry) | | | |
| Open to CAMHS | 82 (78.1) | 88 (49.7) | < 0.001 |
| Social services involvement | 84 (79.2) | 141 (79.7) | 0.933 |
| Youth Offending Team input | 8 (7.5) | 53 (29.8) | < 0.001 |
| Gang worker involvement | 3 (2.9) | 17 (10.8) | 0.020 |
| National Referral Mechanism | 2 (2.1) | 9 (5.3) | 0.209 |
| ≥3 services involved | 37 (37.0) | 55 (31.4) | 0.346 |

Note: The No NDD group excludes those awaiting assessment for any NDD; EHCP = Education and Health Care Plan; NEET = Not in Education, Employment or Training. Sample sizes differed across variables due to missing or unavailable data; reported n values are the maximum for any given variable. p values were calculated from chi-square (significant associations are emboldened).

OR=0.19, 95 % CI=0.09, 0.42), and gang worker involvement (3, 2.9 % vs 17, 10.8 %; p=0.020; OR=0.25, 95 % CI=0.07, 0.88). There was a significant difference (p<0.001) in educational placement between those with ASC and those with no-NDD, with only one-third (34, 32.1 %) of those with ASC being in mainstream education compared to almost half (78, 45.6 %) of those with no-NDD. Almost half of those with ASC were in a specialist educational placement (57, 53.8 %); the odds being almost three times greater than for those with no-NDD (OR=2.84, 95 % CI=1.62, 4.98). A further 15 (14.2 %) were out of education. Notably, females with ASC were more often out of education than males with ASC (7 of 18 females vs 8 of 88 males; p<0.001; OR = 6.36, 95 % CI=1.93, 21.01); there was no statistical difference in ethnic backgrounds for those with ASC out of education. CYP with ASC more frequently had an Educational and Healthcare Plan (EHCP; aimed at ensuring an individualised education support plan) in place on referral than those with no-NDD (OR=18.01, 95 % CI=9.41, 34.47) but, whilst 68 (64.2 %) of those with ASC had an EHCP this did not include all of those out of mainstream education.

3.6. Reasons for referral and referring service

Almost half (45, 42.5 %) of CYP with ASC were referred due to violent behaviours, most of which (30, 28.3 %) were in the home. Whilst the overarching reasons for referral for CYP with ASC and with no-NDD were not significantly different (p = 0.160), the odds of those with ASC to be referred for violence specifically in the home were more than 3 times greater than those with no-NDD (OR = 3.30, 95 % CI=1.75, 6.24; Table 3). The referring agency was significantly different between CYP with ASC and with no-NDD (p < 0.001); the main difference was that almost two-thirds of CYP with ASC (65, 61.3 %) were referred by mental health services compared to about one-third of those with no-NDD (71, 39.9 %, p < 0.001; OR=2.39, 95 % CI=1.46, 3.91).

3.7. Level of risk as clinically assessed at NWLFCAMHS referral

Considering risk of those with ASC (Fig. 3), as assessed by an NWLFCAMHS clinician; a small majority were low risk to self (58, 56.3 %) and moderate risk to others (61, 59.2 %) while nearly half were moderate risk from others (43, 42.6 %). Notably, almost a third were assessed as high risk to others (32, 31.1 %) and at high risk from others (29, 28.7 %). The NWLFCAMHS assessed level of

Table 3Reason for referral, referring service and input level and outcome according to ASC diagnostic status.

| | ASC | No NDD | ASC vs No NDD |
|---|-----------|------------|------------------|
| | n (%) | n (%) | р |
| NWLFCAMHS referral | n = 106 | n = 178 | |
| Primary reason for referral | | | |
| Violence | 45 (42.5) | 63 (35.4) | |
| Offence related behaviour | 20 (18.9) | 25 (14.0) | |
| Verbal threats | 12 (11.3) | 11 (6.2) | |
| Exploitation | 9 (8.5) | 25 (14.0) | |
| Transition/needs in secure | 5 (4.7) | 11 (6.2) | |
| Request for second opinion | 10 (9.4) | 28 (15.7) | |
| Other | 5 (4.7) | 15 (8.4) | 0.160 |
| Violence as reason for referral | | | |
| Violence in home | 30 (28.3) | 19 (10.7) | < 0.001 |
| Violence in school/community | 9 (8.5) | 23 (12.9) | 0.253 |
| Violence across more than one setting | 6 (5.7) | 21 (11.8) | 0.088 |
| Sexually harmful behaviour | 19 (17.9) | 20 (11.4) | 0.127 |
| Main referring service | | | |
| Mental health | 65 (61.3) | 71 (39.9) | |
| Local authority | 31 (29.2) | 76 (42.7) | |
| Education | 9 (8.5) | 12 (6.7) | |
| Youth Justice Services | 0 (0.0) | 15 (8.4) | |
| Other (Health, Family, Voluntary agency) | 1 (0.9) | 4 (2.2) | < 0.001 |
| NWLFCAMHS input | n = 93 | n = 168 | |
| Maximum input level received | | | |
| Informal brief advice | 19 (20.4) | 62 (37.6) | |
| Ongoing consultation/Multiagency meetings | 45 (48.4) | 64 (38.8) | |
| Notes assessment/Multiagency formulation | 19 (20.4) | 22 (13.3) | |
| Direct assessment/Joint intervention | 10 (10.8) | 17 (10.3) | 0.033 |
| Length open to NWLFCAMHS | | | |
| One-off/up to 1 month | 16 (17.2) | 68 (40.5) | |
| 1–6 months | 50 (53.8) | 65 (38.7) | |
| >6 months | 27 (29.0) | 35 (20.8) | < 0.001 |
| Satisfaction with discharge plans | 75 (80.6) | 126 (75.0) | 0.299 |
| Ongoing multiagency care plans | 77 (87.5) | 110 (74.8) | 0.020 |

Note: The No NDD group excludes those awaiting assessment for any NDD; Sample sizes differed across variables due to missing or unavailable data; n values for ASC and No NDD groups under NWLFCAMHS referral and input headings are the maximum for any given variable; percentages were calculated from available data only. p values were calculated from chi-square (significant associations are emboldened).

risk to self and to others, was similar for those with ASC and those with no-NDD but significantly different for risk from others (p = 0.042); the odds of CYP with ASC to be considered at high risk from others were almost half that of CYP with no-NDD (OR = 0.51, 95 % CI = 0.30, 0.87). For CYP with ASC, there were no significant differences in age, gender, ethnic background or NEET status in those considered to be at high risk to others and those who were not (for all comparisons, p > 0.172).

3.8. NWLFCAMHS input

Close to half (45, 48.4%) of CYP with ASC referred to NWLFCAMHS had indirect input including ongoing consultation and attendance at multiagency meeting, one-fifth (19, 20.4%) had a higher level of indirect involvement including a notes assessment and/or multiagency formulation, and one-fifth (19, 20.4%) had brief one-off advice. One-tenth (10, 10.8%) had direct input to include an assessment and/or joint intervention work with NWLFCAMHS and local services. This was significantly different (p = 0.033) from those with no-NDD; those with ASC had proportionally less referrals using brief one-off advice than those with no-NDD (19, 20.4% vs 62, 37.6%; OR=0.44, 95% CI=0.24, 0.80). Reflecting this, whilst a similar number of CYP with ASC (66, 71%) and no-NDD (133, 79.2%) were open to NWLFCAMHS for under 6 months, the majority of CYP (50, 53.8%) with ASC were open to NWLFCAMHS for 1–6 months, compared to almost half of CYP with no-NDD (68, 40.5%) open for only a brief one-off consultation.

3.9. Changes during NWLFCAMHS input

At discharge, the proportion of CYP with ASC that posed a high risk to others and were at high risk from others reduced significantly, with a comparable decrease in CYP with no-NDD (for all within-group mid-p McNemar's tests, p < 0.011; Fig. 4). Differences between referral and discharge for high risk to self was not significant for either group however (for both mid-p McNemar's tests, p > 0.070), although base-rate proportions were low at both periods. On discharge, NWLFCAMHS clinicians were satisfied with the discharge plans for four-fifths (75, 80.6 %) of the CYP with ASC, a similar rate to those with no-NDD (125, 75.0 %). Significantly higher rates of CYP with ASC had ongoing multiagency care plans on discharge (77, 87.5 % ASC vs 110, 74.8 % no-NDD, p = 0.020) and 3 services involved on discharge (OR=1.75, 95 % CI=1.05, 2.93).

4. Discussion

This study is the first to focus on the needs of CYP with ASC referred to a C-FCAMHS team in England. Consistent with previous

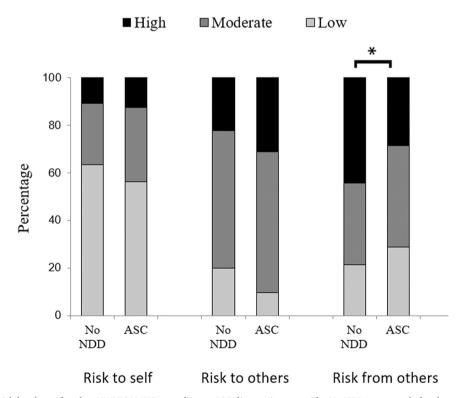


Fig. 3. Observed risk level at referral to NWLFCAMHS according to ASC diagnostic status. The No NDD group excludes those awaiting assessment for any NDD; ASC group includes young people with comorbid ADHD and/or LD. Pairwise differences between groups are indicated by an asterisk (*p < 0.05).

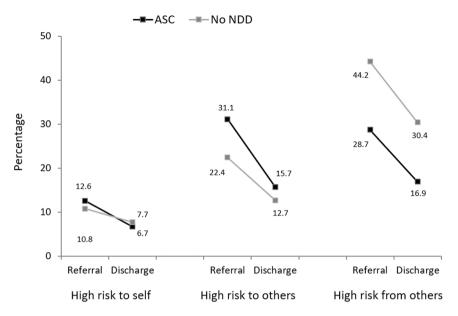


Fig. 4. Percentage with high risk level observed at referral to and discharge from NWLFCAMHS according to ASC diagnostic status. The No NDD group excludes those awaiting assessment for any NDD; ASC group includes young people with comorbid ADHD and/or LD. Data labels represent percentage values. Differences between referral and discharge for risk to self was not significant for either group (for both mid-p McNemar's tests, p > 0.070). Differences between referral and discharge for both risk to other and risk from others were significant for each group (for all mid-p McNemar's tests, p < 0.011).

studies (Lane et al., 2021; Smith et al., 2022) a quarter of our referrals had ASC, a much higher prevalence rate than that estimated in the UK community (Russell et al., 2022). ASC alone is insufficient to warrant a referral to C-FCAMHS and these studies indicate that there is a large group of CYP with ASC with co-occurring difficulties associated with, or accentuated by, their ASC traits such that they develop risk behaviours. As ASC is an NDD, present throughout life, early identification and proactive educational and social support in early life and school may reduce risk behaviours developing (Okoye et al., 2023). Further analyses of the needs and service offered to those with ASC referred to our service highlighted areas where extra support may be possible to reduce future risk.

There were more males with ASC, consistent with findings in the general population (Health and Social Care Information Centre, 2018), though rates of ASC in referred girls were disproportionally higher than that for boys. This suggests that girls with ASC are at greater risk of developing risk behaviours than boys. It is now known that girls with ASC are often diagnosed later than boys because they mask their symptoms (Belcher et al., 2023) and the standardised assessment tools are validated more for use with boys, perhaps leading to missed opportunities to support girls earlier in their childhood and avoid traumatic experiences due to social difficulties (Simcoe et al., 2023). We found that girls with ASC were at a higher risk of being out of education compared to boys with ASC. Masking difficulties, as seen more often in girls, causes anxiety and distress. This can be associated with both poor school attendance and risk behaviours (Allely et al., 2017). Notably, poor school attendance gives a CYP more time to associate with delinquent groups, and conversely, school exclusions follow risk behaviours. Whilst pathways are not yet clear, better early identification of ASC and formulation of needs may enable appropriate support to be put in place and reduce the development of risk behaviours in girls.

Similarly, although there were higher rates of ASC in CYP referred to NWLFCAMHS in those who were White compared to those from racialised backgrounds, rates in those from racialised backgrounds appeared exponentially higher in our referral population than the general population (Health and Social Care Information Centre, 2018). We considered missed opportunities in identifying and assessing those from racialised backgrounds. Notably, we referred a similar proportion of CYP from White, Black and Asian backgrounds for assessment and a similar number were diagnosed. It may be that our team also found it difficult to identify ASC in CYP from racialised backgrounds (Roman-Urrestarazu et al., 2021). Further training is needed to enable professionals to identify ASC in diverse groups. However, given only one-quarter of the CYP who had an ASC assessment whilst on NWLFCAMHS referral were found to fulfil diagnostic criteria, the question arises as to whether the standard Autism Diagnostic Observation Schedule (ADOS) assessment tool is appropriate for this population of adolescents or whether we are considering ASC to explain the needs of many without ASC.

Our findings suggested that there are many with ASC who have co-occurring neurodevelopmental conditions. In a comprehensive thematic review, Hus and Segal (2021) highlighted the need to always consider co-occurrence at the point of assessment to avoid misdiagnoses, especially in socio-culturally diverse families. They called for enhanced longitudinal studies to determine shared characteristics of groups of children with ASC, suggesting that not only would this reduce the chances of misdiagnosis, but also assist with mapping out individual CYP functional profiles leading to interventions. By establishing these individual functional profiles, CYP and their families can become more aware of their weaknesses, strengths and talents, leading to tailored support.

We considered services already offered to CYP with ASC referred to NWLFCAMHS to identify where there may have been missed opportunities in supporting CYP with ASC, aimed at avoiding development of risk behaviours. CYP with ASC were more likely to have

CAMHS involvement than those without, similar social care input, and less input from YOT and gangs' workers. Furthermore, significantly fewer CYP with ASC were in mainstream education and whilst many of those with ASC who were out of mainstream education were in special education and had an EHCP, this was by no means seen in all CYP with ASC. As there is no specific 'CAMHS treatment' for ASC and recommendations are for environmental adaptions, we were concerned to find that not all CYP with ASC (showing sufficient risk behaviour to warrant referral to NWLFCAMHS) had social care support or an EHCP for educational support. Having multi-agency coordinated care plans would likely mitigate risks present and early support could stop the development of secondary mental health difficulties, experience of trauma and subsequent risk behaviours (Connelly & Platt, 2014; Hosozawa et al., 2021; Widnall et al., 2022).

On the positive side, CYP with ASC referred to NWLFCAMHS were not being criminalised by services and more likely to be living at home than those without ASC and less reported experience of trauma. While population-based studies suggest ASC CYP exhibit higher risk behaviours and have a greater likelihood of experiencing stressful and traumatic life events compared to neurotypical individuals (Fuld, 2018; Ly et al., 2023), the CYP under study here were, by definition, at risk or evidencing risk behaviour with high rates of involvement with the justice system and traumatic experiences. As such, the differences may reflect increased support available for those with a diagnosis of ASC relative to those without.

Most CYP with ASC were referred to NWLFCAMHS due to violent behaviours in their family home. In contrast, those without ASC showed more violence outside of the family home. Notably, CYP with ASC may have more time at home, as more were living with family and many were out of mainstream schooling, especially post Covid when those with ASC struggled to return to full time schooling. Furthermore, CYP with ASC often do their best to manage at school leading to risk behaviours being seen at home when they are relaxed. Another cause of violence in the home are interception needs; Muskens et al. (2017) observed that CYP with ASC who struggled to verbally express their symptoms of pain and medical co-morbidities, tend to exhibit disruptive behaviours.

Whilst one-third of CYP were clinically assessed to be at high risk to others and from others, the overall risk profiles for those with ASC and those without, were similar (risk to self and others) or lower (risk from others) than those with no-NDD. Perhaps the fact that many were living at home with family support mitigated this risk. We were not able to identify any factors associated with being a higher risk to others. The FARAS tool (Al-Attar, 2018) offers a helpful framework to consider risks to other in those with ASC. Future studies using this framework and more specific vulnerability factors about school support, experience of trauma and physical health needs may enable easier identification of those at high risk who need more support.

Most CYP were open to NWLFCAMHS for up to 6 months and input was similar for CYP with and without ASC, with the exception that those without ASC more often needed a brief one-off intervention only. Notably, more CYP with ASC had a multiagency care plan on discharge highlighting the ongoing complexity of needs for CYP with ASC. Therefore, it would be appropriate to suggest further investment and improvement in this pathway for CYP with NDD in the YJS and forensic mental health services. Lane et al. (2021), in their evaluation of FCAMHS in England, also noted an urgent need of identification and appropriate response to CYP with ASC within the YJS.

5. Limitations

Data used for these analyses were part of a larger service evaluation of NWLFCAMHS and therefore not always specific to a study of ASC needs. The study was cross-sectional (at point of referral) and, therefore, could only identify association and not causation, and a number of comparisons were administered without correction for multiple testing. Furthermore, the sample representation may not portray similarly across UK; the sample were derived from CYP referred to one C-FCAMHS service only. A longitudinal national sample of CYP with ASC and risk behaviours, with questions informed by this initial data analyses, would provide a wider and more fine-grained investigation of the needs of CYP with ASC and how to prevent the development of risk behaviours.

There is a long wait list for ASC assessment in community services and many of those referred to NWLFCAMHS were on the waitlist for an assessment. As being on a waitlist does not necessarily lead to a diagnosis of ASC, we included in our ASC group only those individuals who had a confirmed diagnosis of ASC upon discharge, or for those not closed, a confirmed diagnosis on referral. Therefore, it is possible that we underestimated the prevalence of ASC in our sample. Finally, as the data were from a service evaluation, we did not have specific information to assess individual needs when evaluating the risk behaviours and services responses, but rather made assumptions of needs based on services involved.

6. Recommendations

A review of the effectiveness of our diagnostic tools for Autism in adolescents who engage in risk behaviours is needed to support assessment and care planning for this group of CYP. More specifically, we recommend a review of diagnostic tools for Autism in young children who are female or from sociocultural diverse backgrounds (Tromans et al., 2021) to ensure that there is equal access for early identification of needs and support for children who may later develop risk behaviours. Furthermore, studies with diverse groups are needed to explore how parents from racialised groups can be empowered through awareness about ASC (and decreased stigma associated with ASC) to enable earlier referrals for assessment and support to be made.

Further research using a larger sample of CYP in contact with C-FCAMHS and the youth justice service, considering their mental and emotional health, educational and social care needs and specific risk behaviours, would help to further understand the needs of this population group and how to support them in the community and if they are detained in a secure institution. More specifically, studies that consider risk factors for child-to-parent violence and trials of innovative interventions to reduce this risk and support the CYP and their family are needed. Increased resources for and access to interventions currently available, such as Non-Violent

Resistance (NVR), sensory assessments and Positive Behavioural Support (PBS), would reduce distress and risk (National Autistic Society, 2024; Oxford Health NHS Foundation Trust, 2024).

7. Conclusions

This paper demonstrates clinically relevant information on the missed opportunities to support children with ASC before they show risk behaviours. Educating and informing professionals working with young children to identify those with neurodiversity, with services able to assess with diagnostic tools valid across all sociocultural and gender diverse groups, will enable early identification. Supporting autistic children in autism friendly educational settings, with individualised EHCPs (or Individual Development Plans in Wales) and use of neurodevelopmental profiles enabling them to identify their needs, strengths and weaknesses, will facilitate positive experiences in childhood that could remove risk factors for risk behaviours in adolescents. Children with neurodiversity can present with different needs and risks throughout their childhood and as such there is a need for ongoing multiagency working to ensure regular review of the need to adapt the environment and support children and their parents. As this group have complex needs, they are already at a higher likelihood of escalation of their risk threshold and need for detention. Further investments in resourcing early intervention may prevent these individuals from entering secure care (Hales et al., 2022).

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CRediT authorship contribution statement

H. Hales: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – review & editing. E. Curtis: Data curation, Investigation, Writing – review & editing. C. Benn: Data curation, Investigation, Writing – review & editing. B. Ross-Michaelides: Methodology, Writing – review & editing. D. Moran: Data curation, Investigation, Writing – review & editing. M. Sandiford: Data curation, Investigation, Methodology, Writing – review & editing. J.G. Smith: Data curation, Formal analysis, Methodology, Writing – review & editing. A. Sri: Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

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Data availability

Data will be made available on request.

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