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Primary neurodevelopmental disorders in detained adolescents: point prevalence and patterns of care

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ABSTRACT

Limited information is available on the numbers and trajectories of detained young people with Neurodevelopmental Disorders (NDD) disorders. We completed a census in all types of secure establishments for young people from England. From this, we sought to find the point prevalence of Neurodevelopmental Disorders in young people in secure settings. A quarter of 1322 young people in secure care had at least one NDD; for 204 (18.5%) this was a primary diagnosis. The most common primary diagnosis was ADHD, 101 (9%), followed by 55 (5%) young people with LD and 48 (4%) with ASC. All young people with a primary NDD had had contact prior to detention with at least one of the statutory agencies. More of those with a primary NDD were moved to their current secure placement from a secure placement than those young people with an NDD is insufficient to prevent significant numbers developing a level of challenging behaviour that requires secure provision. The large numbers of such young people, especially young men, who are detained in the YJS is a grave concern.

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KEYWORDS Young people; secure; neurodevelopmental; ADHD; ASC; learning difficulties

Introduction

The needs of individuals with neurodevelopmental disorders (NDD) have been protected in England and Wales, within The Autism Act, 2009 (Houses of Parliament. The Autism Act, 2009), and as 'protected characteristics' under disabilities in The Equality Act, 2010 (Houses of Parliament. The Equality Act, 2010). Risks of institutional care for individuals with these characteristics have been highlighted (e.g., Winterbourne View) leading to recommendations, only partly achieved (Bubb, 2014), that community placements be used wherever possible.

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Figure 1. The secure estate to young people in England (Hales et al, 2018). Note: YJS = Youth Justice System; YCS = Youth Custody System; YJB = Youth Justice Board; CQC = Care Quality Commission; HMIP = Her Majesty's Inspectorate of Prisons.

The secure system for young people in England is complex; young people requiring secure care can be detained under three different types of legislation in four types of establishment (see, Figure 1). Those detained under the youth justice system can be placed in three different types of placement escalating up to a more adult type establishment depending upon their age, risk and vulnerability, namely: secure children's homes (SCHs), secure training centres (STCs) or young offender institutions (YOIs). Children detained under The Children Act under welfare needs are detained into Secure Children's Homes (SCHs). Those with mental health needs can be detained under the Mental Health Act into secure hospitals for adolescents.

Young people in secure care in the UK have high rates of NDD (Hughes et al., 2012). Policy review has highlighted the failure to identify and manage NDD problems in young offenders (APPGA All Party Parliamentary Group on Autism, 2019; Hughes et al., 2012), despite recommendations for diversion to health settings from custody (Bradley, 2009), and to improve identification and management of health vulnerabilities (Hughes et al., 2012). Current understanding is hampered by the lack of large secure care samples

(Chitsabesan et al., 2006), and lack of information on some types of NDD (Chitsabesan et al., 2006; Kroll et al., 2012). Also, most papers only study a single type of secure setting (Beaudry et al., 2020; Hill et al., 2016, 2014).

Recognition of the previous methodological difficulties and ongoing needs of young people led to a three part study of all secure care (mental health, welfare and youth justice) for young people from England (Bartlett et al., 2018; Hales et al., 2018; Warner et al., 2018). Basic census information from the study of 1322 young people from England in secure care found rates of NDD in all sectors of secure care were substantially higher than in the general adolescent population (Warner et al., 2018). This paper describes further analyses of this data, to investigate:

- the overall point prevalence of primary diagnoses of ADHD (Attention Deficit Hyperactivity Disorder), ASC (Autistic Spectrum Condition), LD (Learning Disability);
- (2) pathways into secure care; and,
- (3) placement and input for those with primary diagnoses of ADHD, ASC and LD in secure care.

Methods

In 2016 a scoping of all secure establishments in the UK (England, Scotland, Wales) was completed (Warner et al., 2018) followed by a census on 14. 09. 16 (Hales et al., 2018). Full details of the methodology used to obtain the basic census data and undertake the initial analysis are described in Appendix B of that report. Information pertinent to this further analysis is described below.

The HRA (Health Research Authority) confirmed that ethical approval was not required as this was a service evaluation. CAG (Confidentiality Advisory Group) approval was given (CAG reference 16/CAG/0097). Each healthcare provider ensured local clinical governance approval.

A nominated staff member coordinated the health/care staff to complete pseudo-anonymised data sheets on each young person, containing information including:

- (1) demographics (gender, age, ethnicity);
- detaining legislative framework;
- (3) number and type of previous placements;
- (4) previous service input; and,
- (5) clinical needs/risk and diagnoses (in open written text).

For some big sites (the largest SCH, one STC and all YOIs), LW was the nominated staff member to collect data from the electronic medical notes.

4 👄 H. HALES ET AL.

Diagnostic classifications were coded by our adolescent forensic psychiatrist (HH) who reviewed all text written about mental health needs, diagnosis, risks and reason for detention to make a clinical opinion of whether those needs would fulfil a specific diagnostic category. As there was much co-morbidity within the sample of young people, a clinical view was taken about the predominant clinical need, which was listed as the primary diagnosis. This was prioritised, by considering mental health care pathways, with acute mental health illnesses such as psychosis and depression first and then neurodevelopmental needs or emerging personality disorders with regards to description of needs and risk. Within the cluster of NDDs, LD was prioritised over ASC, which were prioritised over ADHD. There were too few with NDDs other than LD, ASC, ADHD to be analysed separately. These were listed together as 'other'. If there was no written information about diagnoses, risk or mental health needs, this was listed as missing data.

Statistical analyses

Descriptive data is presented using frequencies and percentages. Chisquare and Fisher's exact tests were employed to compare categorical data, with (post-hoc) pairwise comparisons administered where significant differences were observed (these associations were described in the form of odds ratios (ORs) with 95% confidence intervals (CIs)). The false discovery rate (FDR) approach, controlled at level $\alpha = 5\%$ (Benjamini & Hochberg, 1995) was applied to analyses involving the complete sample (e.g., comparing those with a primary NDD to other young people) to determine statistical significance. For all other analyses (including those concerning comparisons between primary LD, primary ASC and primary ADHD), the criterion for statistical significance was set at P < 0.05. All statistical analyses were completed with the SPSS (IBM, Version 22.0).

Results

Response rates

On 14 September 2016, there were 1322 English children in secure care; 983 (76.9%) young men, 290 (22.7%) young women, five (0.4%) individuals identified as transgender and one (0.1%) as intersex (gender was not recorded for 43 young people). Almost all, 1260 (95.3%), were placed in England with the other 62 (4.7%) placed in Wales or Scotland. The majority were placed in youth justice beds (903, 68.3%), with almost a quarter placed in secure hospital (312, 23.6%) and a small proportion placed in secure welfare (107, 8.1%). For those in youth justice beds, the majority (668, 50.5%) were placed in YOIs, 124 (9.4%) in STCs and 111 (8.4%) in youth justice beds in SCHs. More detailed sociodemographic data for these young people has previously been described (Hales et al., 2018).

Prevalence of primary diagnosis of neurodevelopmental disorders

Data concerning diagnosis of NDDs were available for 1105 (83.6%) young people. Missing NDD data were more frequent for young people placed in Welfare (47.7%) than those placed in Secure Hospital (10.9%) or in Youth Custody (14.6%; p < 0.001).

Two hundred and four (18.5%) young people on whom there were data were reported to have a primary diagnosis of a NDD. Another 85 (7.7%) were diagnosed with a NDD but this was secondary to another psychiatric diagnosis. The numbers of young people with primary diagnoses of LD, ASC and ADHD were 55 (5.0%), 48 (4.3%) and 101 (9.7%), respectively. Twenty-six (2.4%) young people had a secondary diagnosis of LD, 70 (6.3%) a secondary diagnosis of ASC (21 with primary LD) and 74 (6.7%) a secondary diagnosis of ADHD (21 with primary LD and 22 with primary ASC). At the time of the census, LD was being assessed or queried in eight more individuals, ASC assessed or queried in 17 young people and ADHD assessed or queried in 17 individuals.

Sociodemographic differences between individuals with primary NDD are explored in Table 1. A fifth of young men have a primary NDD compared to 12.7% of young women, a more than 70% increase in relative rate. This difference was predominantly due to a more than 10-fold increase in associated risk of a primary ADHD diagnosis in young men. White young people in secure care were more likely than young people from racialized groups to have a primary NDD (an increase in odds of 1.77), which was largely attributable to higher rates of LD and ASC in young white people.

Types of input to young people prior to their current detention

All young people with a primary diagnosis of NDD had had prior contact with one or more of relevant agencies; social care (98, 68.1%), youth justice (Youth Offending Teams (YOT); 139, 80.3%) or health (Child and Adolescent Mental Health Services (CAMHS); 166, 85.6%) agencies. Almost half (60, 49.2%) had a previous contact with all three types of agencies. Rates of previous contact with welfare and health agencies were comparable across different NDDs (Figure 2), but previous contact with YOT was significantly more frequent for those with a primary diagnosis of ADHD compared with LD (OR = 6.23, CI = 2.37, 16.38, p < 0.001) and ASC (OR = 3.68, CI = 1.36, 10.01, p = 0.006).

Table 1. Rates of Prima age and ethnicity.	ary Neurod	evelopmental [Disorders (NI	ODs) and Prim	ary Non-N	VDDs in detai	ined youn	g people from l	England acco	rding to gender,
	No Diagnosis	Primary Non-NDD	Primary NDD	Primary NDD	Primary Lea	arning Disability	Primary Au Co	utistic Spectrum Indition	Primary A Hyperact	ttention Deficit ivity Disorder
	(%) <i>u</i>	(%) u	(%) u	OR(95% CI)	(%) u	OR(95% CI)	0%) <i>u</i>	OR(95% CI)	(%) <i>u</i>	OR(95% CI)
Gender Male (<i>n</i> = 854) Female (<i>n</i> = 244)	482 (56.4) 30 (12.3)	201 (23.5) 183 (75.0)	171 (20.0)*** 31 (12.7)	1.72**(1.14,2.60)	38 (4.4) 17 (7.0)		36 (4.2) 11 (4.5)		97 (11.4)*** 3 (1.2)	10.29 (3.23,32.77)
Age ≤15 years (<i>n</i> = 183)	74 (40.4)	63 (34.4)	46 (25.1)		10 (5.5)		12 (6.6)		24 (13.1)	
16-17 years ($n = 787$)	401 (51.0)	260 (33.0)	126 (16.0)		32 (4.1)		29 (3.7)		65 (8.3)	
18+ years (<i>n</i> = 71) Ethnicity	30 (42.3)	29 (40.8)	12 (16.9)		3 (4.2)		4 (5.6)		5 (7.0)	
White $(n = 619)$	242 (39.1)	243 (39.3)	134 (21.6)***	1.77** (1.24,2.52)	41 (6.6)**	2.50 (1.24,5.05)	40 (6.5)***	4.93 (1.93,12.62)	53 (8.6)	
Racialised groups ($n = 362$)	221 (61.0)	92 (25.4)	49 (13.5)		10 (2.8)		5 (1.4)		34 (9.4)	
Black ($n = 174$)	115 (66.1)	34 (19.5)	25 (14.4)		5 (2.9)		5 (2.9)		15 (8.6)	
Asian ($n = 56$) Mixed/Other ($n = 132$)	(5.20) 62.7 71 (53.8)	18 (32.1) 40 (30.3)	3 (5.4) 21 (15.9)		1 (1.8) 4 (3.0)		0 (0.0) 0 (0.0)		2 (3.6) 17 (12.9)	
Note: N values differ acros transgender young persc while one transgender y differences between 'No (described with OR and 9	s variables du on was report oung person Diagnosis', 'P 35% CI) are hi	ue to missing dat ed as having a pri a and one interse: rimary Non-NDD' ghlighted in bold	a concerning (mary diagnosis x young perso and 'Primary N	orimary) psychia of Autistic Spect n had a primary DD' groups (fron < 0.01, ***p < 0	tric (NDD a trum Condi non-NDD n Chi-squar 1.001.Gende	nd non-NDD) d tion, another ha diagnosis – the e tests, correcte er comparisons	liagnoses (<i>n</i> ad a primary ese were no ed for multip were made	= 217) and relevated diagnosis of Atter t included in ana le comparisons) al between Male and	ant sociodemo ntion Deficit Hy lyses involving nd significant p d Female young	graphic factors; One peractivity Disorder, gender; Significant airwise associations people – reference
category for odds ratio ((OR) is female;	; Ethnicity compar	isons were ma	de between you	ng people	identifying as M	/hite and th	ose from Racialise	d groups (the l	atter includes Black,

Asian and Mixed/Other ethnicities) – reference category for OR is Racialised groups; No within-group differences were observed between Black, Asian and Mixed/Other ethnicities.

H. HALES ET AL.

6



Figure 2. Young people with NDDs known to Welfare, Youth Justice and Child and Adolescent Mental Health Services (CAMHS) on detention. Note: Data regarding previous contact with social services, youth offending team and CAMHS was not available for 60, 32 and 10 (of the 204) young people with a NDD, respectively. Asterisks indicate significant differences across the 3 groups, ***p < 0.001.

Some young people were discharged from CAMHS whilst in detention and others referred to CAMHS from detention. Of the 84 young people with ADHD who were known to CAMHS immediately prior to detention, more than onethird (30, 35.7%) had been discharged during detention, leaving a little over half (47, 56%) open to CAMHS at the time of the census (post-detention data was not available for seven young people). Four of the 12 young people with primary ADHD not open to CAMHS immediately prior to detention were referred during detention. Thirteen of 42 (32.5%) young people with ASC with previous CAMHS contact were discharged from CAMHS after they were detained (post-detention data was not available for two young people) and only one of the four people not open to CAMHS prior to detention were referred from their current place of detention.

Pathways into secure care

The most recent change of placement was not necessarily linked to identified NDD needs. Current secure placement (legislative framework) was significantly associated with the setting from where young people were transferred, considering primary LD, primary ASC, and primary ADHD separately (Figure 3; for all comparisons, $\chi^2(6) > 16.39$, p < 0.013). This reflected the strong tendency for young people moved from their home to be placed in youth custody rather than in a secure hospital, and for those in hospital (open or secure) or welfare (open or secure), to be placed in the same type of institution (now secure).



Figure 3. Secure care pathways of young people in secure care with Primary Learning Disability (LD), Primary Autistic Spectrum Condition (ASC) and Primary Attention Deficit Hyperactivity Disorder (ADHD) according to legislative framework (centre row of figure: Welfare (Children Act), Mental Health Act, Youth Justice System) under which currently placed.

All young people with a primary NDD who had been transferred from another youth custody setting remained in youth custody (including three people with LD where there is a known pathway to secure hospital). Those with an NDD originally based in hospital largely stayed in hospital, albeit now secure hospital; the exception was two young people (both of whom had LD). There was no apparent pattern to the movement from welfare settings.

Just over half the young people with a primary NDD had been in a previous secure placement at some point of their lives (Table 2); this rate was comparable across different NDDs and to those with no diagnosis or a primary non-NDD. But almost one in five young people with at least one NDD were moved to their current secure placement from another secure setting, a rate significantly higher than individuals with no diagnosis. Less than half (two-fifths) of young people with an NDD were detained from their home, a two-thirds decrease in odds relative to those without a diagnosis. Another 40% were transferred to secure care from a welfare setting, a more than twofold increase in rate compared to those without a diagnosis, while almost 13% were transferred from hospital, a significantly higher rate than those without a diagnosis although much less than those with a primary non-NDD.

The setting from which young people were transferred differed according to primary NDD type ($\chi^2(6) = 30.05$, p < 0.001; Table 3). Young people with LD were less frequently admitted from their home (family/community) than both those with ASC or ADHD, reflecting a more than 60% decrease in odds for each, and disproportionally more often admitted from hospital and from another secure setting than those with ADHD.

Table 2. Care pathways of yo	ung people in sec	ure care with Primary	y Neurodevelopm	nental Disorders (NDDs) and Pri Democry NDD vie Discovers	imary Non-NDDs.
	NO Ulagnosis		Primary NUU	Primary INUU VS. NO Diagnosis	Primary NUU VS.Primary Non-NUU
	n (%)	n (%)	n (%)	OR (95% CI)	OR (95% CI)
Previous secure experience	n = 485	<i>n</i> = 364	<i>n</i> = 187		
Previous secure placement	224 (46.3)	197 (52.7)	103 (52.8)		
Admitted from secure setting	66 (13.6)	85 (23.4)	37 (19.8)**	1.57 (1.01,2.44)*	0.81 (0.53,1.25)
Setting transferred from	n = 485	n = 363	<i>n</i> = 187		
Community family	321 (66.2)	115 (31.7)	75 (40.1)***	0.34 (0.24,0.48)***	1.44 (1.01,2.08)*
Welfare	110 (22.7)	70 (19.3)	73 (39.0)	2.18 (1.52,3.14)***	2.68 (1.81,3.97)***
Hospital	1 (0.2)	151 (41.6)	24 (12.8)	71.24 (9.57,530.93)***	0.21 (0.13,0.33)***
Custody	53 (10.9)	27 (7.4)	15 (8.0)	0.71 (0.39,1.30)	1.09 (0.56,2.09)
Note: N values differ across variabl CI) = odds ratio (95% confidence multiple comparisons) and signifi	es due to missing da e intervals); Significant icant post-hoc pairwi	tta concerning (primary) t differences between 'No se associations (described	psychiatric (NDD and o Diagnosis', 'Primary d with OR and 95% (d non-NDD) diagnoses and/or previt / Non-NDD' and 'Primary NDD' grou CI) are highlighted in bold: *p < 0.05	ous placement data ($n = 287$); OR (95%) ps ((from Chi-square tests, corrected for 5, **n < 0.011, ***n < 0.001.

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	Primary LD	Primary ASC	Primary ADHD	Primary LD vs.Primary ASC	Primary LD vs.Primary ADHD	Primary ASC vs. Primary ADHD
	n (%)	n (%)	n (%)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Previous secure experience	<i>n</i> = 51	n = 45	<i>n</i> = 91			
Previous secure placement	27 (52.9)	23 (50.0)	53 (54.1)			
Admitted from secure setting	16 (31.4)	7 (15.6)	14 (15.4)*	2.48 (0.91,6.75)	2.51 (1.11,5.72)*	1.01 (0.38,2.72)
Setting transferred from	<i>n</i> = 51	n = 45	n = 91			
Community family	12 (23.5)	22 (48.9)	41 (45.1)***	0.32 (0.14,0.77)**	0.38 (0.17,0.81)*	1.17 (0.57,2.39)
Welfare	21 (41.2)	13 (28.9)	39 (42.9)	1.72 (0.74,4.04)	0.93 (0.47,1.87)	0.54 (0.25,1.17)
Hospital	15 (29.4)	8 (17.8)	1 (1.1)	1.93 (0.73,5.10)	37.50 (4.78,294.46)***	19.46 (2.35,161.12)***
Custody	3 (5.9)	2 (4.4)	10 (11.0)	1.34 (0.21,8.43)	0.51 (0.13,1.93)	0.38 (0.08,1.80)
Legislative framework	n = 55	n = 48	<i>n</i> = 101			
Mental health	32 (58.2)	18 (37.5)	4 (4.0)***	2.32 (1.05,5.12)*	33.74 (10.85,104.91)***	14.55 (4.57,46.33)***
Welfare	3 (5.5)	2 (4.2)	10 (9.9)	1.34 (0.21,8.29)	0.53 (0.14,1.99)	0.40 (0.08,1.88)
Youth Justice System	20 (36.4)	28 (58.3)	87 (86.1)	0.41 (0.18,0.90)*	0.09 (0.04,0.20)***	0.23 (0.10,0.50)***
Note: N values differ across variab.	les due to miss	ing data concen	ning (primary) NDI	D diagnosis and/or previous pl	acement data ($n = 287$); OR (95%)	CI) = odds ratio (95% confidence
intervals); Significant difference	s between 'Prin	nary LD', 'Primar	y ASC' and 'Primar	y ADHD' groups (from Chi-squ	are tests) and significant post-ho	c pairwise associations (described
with OR and 95% CI) are highlic	ghted in bold;	*p < 0.05, **p <	< 0.01, ***p < 0.00	01.		

	Primary NDD $(n = 204)$	Primary LD $(n = 55)$	Primary ASC $(n = 48)$	Primary ADHD (n = 101)
	n (%)	n (%)	n (%)	n (%)
Mental health				
PICU	15 (7.4)	4 (7.3)	7 (14.6)	4 (4.0)
Low secure	25 (12.3)	19 (34.5)	6 (12.5)	0 (0.0)
Medium secure	14 (6.9)	9 (16.4)	5 (10.4)	0 (0.0)
Welfare				
Secure Children's Home	15 (7.4)	3 (5.5)	2 (4.2)	10 (9.9)
Youth Justice System				
Secure Children's Home	21 (10.3)	6 (10.9)	6 (12.5)	9 (8.9)
Secure Training Centre	22 (10.8)	2 (3.6)	2 (4.2)	18 (17.8)
Youth Offender Institution	92 (45.1)	12 (21.8)	20 (41.7)	60 (59.4)

Table 4. Number (%) of detained young people from England with a Primary Neurodevelopmental Disorder (NDD) placed under each legislative framework (and associated unit).

Note: There was missing data concerning neurodevelopmental disorder (NDD) diagnoses (n = 217) – percentages were calculated according to available data; LD = Learning Disability; ASC = Autistic Spectrum Condition; ADHD = Attention Deficit Hyperactivity Disorder; PICU = Paediatric Intensive Care Unit.

Placement

Table 4 indicates the number (percentage) of detained English young people with primary NDDs according to the unit type in which they were placed). Just over two-thirds of young persons with a primary diagnosis of an NDD were placed under YJS legislation (135/204, 66.2%), where they constituted 17.5% of the population. This is broadly similar proportions to those detained in health (19.4%) and welfare (26.8%) placements but the numbers were far lower.

Learning disability

Almost 60% of young people with primary LD were in hospital (19 young men and 13 young women), a higher rate than those with primary ASC and those with primary ADHD (Table 3). A little over a third of young people with primary LD were placed in youth custody, more than half of which were in YOIs, while only three were placed in secure welfare, all young women, two of whom were in Scottish children's homes. Young people with LD who were already open to CAMHS were more likely to be placed in hospital (27/31, 87.1%) or welfare (2/2, 100%) placements than in youth custody (11/19, 57.9%; $\chi^2(2) = 6.28$, p = 0.043).

12 🔶 H. HALES ET AL.

ADHD

Those with primary LD and ASC were much less frequently placed in the youth custody than those with primary ADHD (all of whom were young men), a 77% and 91% decrease in associated risk, respectively (Table 3). Only four young people (two young men, one young woman and one transgender) with a primary diagnosis of ADHD were in hospital, all in a PICU, detained under Section 2 of the Mental Health Act. Only 42 of the 73 (57.5%) young people with relevant data were having treatment for their ADHD: 11 (15.1%) were on medication and receiving psychological input; 22 (30.1%) on medication alone; and, nine (12.3%) receiving psychological treatment without medication.

Autistic spectrum condition

A small majority of young people with a primary diagnosis of ASC were placed in youth custody, all young men. One young man and one young woman were placed in a secure welfare setting while ten young women, seven young men and one transgender young person were placed in hospital.

Discussion

This paper is the first detailed consideration of young people from England, with primary NDDs, who are detained across the entire secure system (YJS, welfare and secure health care). Our findings support previous studies (Beaudry et al., 2020; Hughes et al., 2012) indicating substantial numbers of young people within the youth justice system have NDDs, and further identifies the primary diagnosis on which care and treatment should be based. From a clinical perspective, a primary NDD should substantially determine what care these young people receive. Patterns of existing placement revealed here allow, for the first time, an evidence-based discussion about service provision across secure care in England.

Missed opportunities and ADHD

Our findings on ADHD raise several concerns. Point prevalence rates of ADHD in secure care are much higher than those in the community, 9% of those in secure care had a primary diagnosis of ADHD, compared to 2% in the community, primary and comorbid (ONS Mental Health of Children and Young People in England, 2017). ADHD is associated with behaviour that can lead to detention in secure care (Mohr-Jensen & Steinhausen, 2016; SJ Young et al., 2018; S Young et al., 2011). It is not, alone, a reason for transfer to hospital under the Mental Health Act as treatment can be offered in the community or in custody. However, it may not be highlighted as mitigating circumstances

within court processes, though there was one notable case when a murder charge was guashed because the young person's ADHD was not raised as affecting his ability to stand trial (Gudjonsson & Young, 2010). Those with ADHD can find being locked in a cell distressing and their impulsivity can get them into trouble with prison officers, leading to a spiral of increased time in cell due to loss of association or exclusion from classes (SJ Young et al., 2018). Whilst most were under CAMHS care prior to detention, one in five were not. Almost a half of those with a primary diagnosis of ADHD were not on any active treatment at the time of the census. Despite effective psychological and pharmaceutical treatment (NICE guideline, 2018), it is interesting that not all were known to CAMHS in the community, and even though some were assessed in custody, almost half received no treatment. This suggests both community and secure mental health services may be missing the opportunity for early intervention to prevent development or continuation of related delinguent behavior. Young people have raised this as a critical issue that could have helped them avoid involvement in the YJS (Peer Power, 2016).

Best practice in ASC

A key concern arising from our data is that rationale for the variety of placements for young people with ASC is unclear. In the absence of agreed guidelines for any intervention, caution is required. Our data can be understood as demonstrating the difficulties all agencies face when considering how and where to support young people with ASC. The vast majority of those young people with ASC were known to CAMHS, fewer were known to other agencies, suggesting the dominant conceptual model of understanding continues to come from health. However, this does not appear to translate into effective healthcare, as more young people with ASC were in custody than elsewhere, despite the fact that custodial settings, for the most part, are not designed for their needs. Those with ASC may have particular difficulties managing in large groups and rigid institutional settings, particularly if the regime conflicts with their usual rituals and if they struggle with noise and bright lights (APPGA All Party Parliamentary Group on Autism, 2019). Prior to detention, community social care support for the family and young person may be more important than community CAMHS. However, the data available suggested that only two thirds were known to social care. Though The Autism Act highlights the particular needs of those with ASC, our results indicate that there continue to be difficulties both in creating individualized integrated multiagency care plans to support young people with ASC in their community placements and in creating expert secure care placements to support those with ASC needing secure care.

14 🔶 H. HALES ET AL.

Failures in social care

These findings show that although there is a clear healthcare pathway for young people with a primary diagnosis of Learning Disability, substantial numbers of young people with these vulnerabilities are in custody, placing them at risk of exploitation by peers. Whilst three quarters were previously known to social care, a quarter have missed out on having an integrated multiagency community care plan, which may have offered more support in the community, preventing exploitation and/or criminalization.

Our findings suggest that community care for those with ASC and LD, more specifically multiagency care planning led by social care in line with the Transforming Care agenda (Bubb, 2014), needs further investment and improvement.

Strengths and limitations

The data described above are from the first comprehensive service evaluation of the entire secure estate for young people in England. This provided a large dataset from which we could consider patterns of needs across primary diagnoses. The data have been provided by professionals working with the young people or from their healthcare notes. Data completion rates were high but data quality (notably detail and consistent use of recognized diagnostic frameworks) was variable across sites. Diagnostic categories and prioritization were reviewed by HH, a consultant adolescent forensic psychiatrist, using the descriptive information given by professionals completing the data forms, about diagnoses, risk and mental health needs. While clinician research interviews would have enhanced diagnostic rigour, this would have been at the expense of comprehensive, in vivo information determining patient journeys.

Conclusions

This paper provides clinically relevant information that could easily inform clinicians and other professionals working with young people whose patient journey crosses agency boundaries and could be used for service redesign. It highlights difficulties in considering where to place those with ASC in the secure system and lack of treatment availability or uptake for those with ADHD in secure care. However, while detailing the current and previous agency contact of detained young people, it leaves open the question as to how many of these young people could have avoided secure care, if pre custody diagnostic, intervention and support services had been better organised and resourced.

Abbreviations

NDD: Neurodevelopmental Disorder, SCH: Secure Children's Home, STC: Secure Training Centre, PICU: Psychiatric Intensive Care Unit, YJS: Youth Justice System, YOI: Young Offender Institution, YOT: Youth Offending Team.

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Author contribution

H Hales and A Bartlett developed the protocol for the service evaluation. H Hales and L Warner worked together on the collection of data. L Warner, H Hales and J Smith completed the data entry and data analyses. All authors were involved in drafting and finalizing the written paper.

Disclosure statement

No potential conflict of interest was reported by the authors.

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Data availability

The data that support the findings of this study are available from the corresponding author (HH) upon reasonable request.

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- 16 👄 H. HALES ET AL.
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