

Awareness within local authorities in England of autism spectrum diagnoses of looked-after children

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Educational outcomes for looked-after children on the autism spectrum are significantly poorer than for autistic children not being looked-after by their local authority (those ‘in care’), and poorer than for most other groups of children with special educational needs who are looked-after in England. Such poor outcomes have led to calls for specific attention to be paid to the needs of autistic looked-after children within the care of local authorities. There is also evidence that the numbers of autistic children being looked-after by local authorities could be under-represented in official figures. This study sought to find the current numbers of autistic looked-after children formally recorded across local authorities in England, and whether their needs are given special attention via strategic planning and oversight, using freedom of information (FoI) requests sent to all local authorities in England. From the 147 (97%) local authorities who responded, approximately 3% of looked-after children in England are recorded as having an autism spectrum diagnosis, although this is still very likely to be an underestimation. The majority of local authorities do not routinely monitor or report on the diagnostic status of autistic looked-after children at a strategic level. Implications for research and practice are discussed.

Keywords: looked-after; local authority; freedom of information; autism; corporate parenting; co-creation

Introduction

According to the Department for Education (2017a), there were 72,670 children being looked-after by local authorities in England as of 31 March 2017. The same statistical release showed that looked-after children in England underachieve relative to their non-looked-after peers at all key stages of education. For example, at Key Stage 1 (age 5–7 years), only 37% of looked-after children reached the expected standard or above in writing compared to 66% of non-looked-after children. At Key Stage 4 (age 14–16 years), only 17.5% of looked-after children achieved five GCSEs at grades A*–C, compared to 58.8% of their non-looked-after peers (Department for Education, 2017a). The risks associated with being placed in care, including abuse,

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neglect or factors that render parents unable to provide adequate care for their children, are compounded by poor associated outcomes of being in the care system, including behavioural, physical and mental health issues (DeJong, 2010). As well as poor educational outcomes, looked-after children are known to have poorer longer-term socioeconomic, psychological and physical health outcomes compared to the general population, and these poorer outcomes are replicated internationally (e.g. see Berridge, 2012 for an overview). In England, under the Children Act 1989, a child is legally defined as looked-after by a local authority if he or she: (a) is provided with accommodation for a continuous period of more than 24 hours; (b) is subject to a care order; or (c) is subject to a placement order. A looked-after child ceases to be looked-after when he or she turns 18 years old.

Children with special educational needs (SEN) are over-represented in the number of looked-after children by a factor of four (Department for Education, 2017a). Looked-after children are also 10 times more likely than all children to be in receipt of a Statement of Special Educational Needs or Education, Health and Care (EHC) Plan (Department for Education, 2017a). The EHC Plan is a formal document that includes the statutory responsibilities of local authorities for supporting children with special educational needs in England, and is usually provided to children with higher levels of support needed. Within the population of looked-after children, those with SEN are, as might be expected, especially vulnerable to poor educational outcomes (O'Higgins *et al.*, 2017). In 2016, 57.3% of looked-after children had SEN compared to 14.4% of all children (Department for Education, 2017a). Reflecting these high proportions, Berridge (2012, p. 1172) highlighted in his review of the education of young people in care that '...more detailed studies of specific groups of children in care, such as by gender or disability' are required.

One of the groups that warrants more detailed study is autistic children,¹ who are at particular risk for poor educational outcomes amongst this already disadvantaged group of looked-after children. In a major analysis of education and social care data in England, Sebba *et al.* (2015) found that children on the autism spectrum were amongst those identified as having SEN, who experienced the poorest educational outcomes of all children who were looked-after by local authorities, with this group second only to children with severe or multiple learning disabilities in terms of the poorest outcomes at Key Stage 4. National figures show that 5.7% ($n = 1,030$) of all children with SEN being looked-after continuously for at least 12 months were recorded as having autistic spectrum disorder (ASD) as their primary need, equating to 1.4% of the population of looked-after children (Department for Education, 2017a). In the general population of children with SEN, those on the autism spectrum represent the largest proportion of children with EHC Plans (28.2%; Department for Education, 2018a), indicating higher levels of support needed for this group.

Interestingly, Sebba *et al.* (2015) also reported that there was very little variation between local authorities with regard to the educational outcomes of looked-after children, and that individual experiences of care and school, as well as the characteristics of the child, were more important in influencing outcomes. This led the authors to conclude that '...sufficient account [should be taken] of the *characteristics of the looked-after children* in each authority' (p. 7, our emphasis). Echoing these sentiments in an unrelated review on the care and support for children and young people with

complex needs involving mental health, learning disabilities and/or autism, Lenehan (2017, p. 15) concluded that:

If this group are not made a national focus for action... then nothing will change. Children with these needs will not go away, and we cannot claim to be effectively planning services based on needs if we pretend they don't exist just because meeting their needs is hard.

Furthermore, in a substantial study into the breakdown of adoptions, Selwyn *et al.* (2014) found that some local authorities did not recognise autism as a disability and so families were unable to access specialised post-adoption support. This led the authors to recommend that local authorities should 'Ensure that there are appropriate services for children whose difficulties are on the autistic spectrum' (p. 290). Taken together, these findings suggest that autism as a specific category of need requires particular recognition by local authorities.

There are two main points from these major reviews that we seek to highlight here, which also lead to the focus of the present study. First, it is clear that appropriate recognition of the specific characteristics and needs of children in care is crucial for the effective planning of services, and in particular to support multi-agency working. The Special Educational Needs and Disability Code of Practice: 0–25 Years (Department for Education/Department of Health, 2015a, sections 1.19 & 3.2) mandates the joint working of relevant parties across education, health and social care to identify, plan for and support the needs of individual children and young people via the integration of services. This means that local authorities, clinical commissioning groups (CCGs) and others must work together to assess needs and use these assessments to inform strategic planning and the commissioning of services. Regarding looked-after children specifically, the same code of practice (section 9.38, p. 151) makes it clear that 'Addressing a looked-after child's special educational needs will be a crucial part of avoiding breakdown in their care placement'. Given the especially poor outcomes for looked-after autistic children, as reported by Sebba *et al.* (2015) and highlighted by Lenehan (2017), we were, therefore, interested in whether and how local authorities recognise the needs of autistic children specifically in their strategic planning for looked-after children. In searching the literature for relevant research in this area, we could not find any evidence that directly addressed this issue at the level of the local authority.

Second, taking 'sufficient account' of the characteristics of autistic children for the planning of services implies that such characteristics are formally identified and known to local authorities. However, there is good evidence that the assessment of neurodevelopmental and/or psychiatric disorders, including autism, is very challenging in the context of multiple and overlapping co-morbidities amongst children in care, which can arise from a range of interrelated factors including prenatal influences, early trauma and disrupted attachment (DeJong, 2010). The social difficulties that lie at the core of an autism spectrum diagnosis (American Psychiatric Association, 2013) can be misclassified in some cases where there is a history of attachment problems and related behavioural and cognitive difficulties (Davidson *et al.*, 2015). Although differential and co-occurring diagnoses between reactive attachment disorder and/or disinhibited social engagement (for example) and autism is possible (Mayes *et al.*, 2016), there is also acknowledgement that sometimes the subtle nature

of differences is very difficult to detect with current assessment measures (Davidson *et al.*, 2015).

In seeking to understand more about this complexity, Green *et al.* (2016, p. 1398) reported an incidence of 11% (6 out of 54) of children with ASD phenotype in a UK sample of adopted children—that is, those who had previously been looked-after by the local authority—with a further 18.5% ($n = 10$) showing ‘partial features’ of autism. This proportion is much higher than the 1–2% prevalence of autism within the general population in England (Baird *et al.*, 2006) and the UK (Russell *et al.*, 2014), and the formally reported figures from the Department for Education (2017a) noted above. However, the Department for Education (2017a) figures showing that 1.4% of the total population of looked-after children have autism as their primary identified need are very likely to be an under-representation of the actual numbers, given the high levels of overlap between SEN categorisations of need (Department for Education/Department of Health, 2015a) as well as the fact that children can also be defined as looked-after by the local authority if they experience periods of accommodation of less than 12 months (not included in the Department for Education, 2017a figures). Overall, these findings suggest that there are likely to be more children being looked-after by local authorities than currently shown in available figures.

In part, this may be because Green *et al.* (2016) identified their sample of previously looked-after (now adopted) children via a mailshot to a national membership charity for adoptive families; thus, families were self-selected rather than systematically sampled. In addition, their sample focused very specifically on children who were adopted rather than those currently being looked-after, which is only a relatively small proportion of the total of looked-after children (only 14%, 4,350, of looked-after children were adopted in 2017; Department for Education, 2017b). Although figures for the overall numbers of looked-after children with SEN in 2016/17 are available by local authority (Department for Education, 2017b), these data do not include a breakdown by primary SEN category. Thus, the numbers of children currently formally recorded as autistic by local authorities in England, including those who have been looked-after for less than 12 months, are not currently known.

As a minimum, this information would help to establish the current snapshot across England of the numbers of formally diagnosed children on the autism spectrum known to be in local authority care. If local authorities are to adequately strategically plan for the needs of autistic children, then they first need to know how many children in their care come under this category. It was, therefore, important for us to find out how many autistic children are currently formally recorded as being in local authority care, and whether information relating to their autism diagnostic status is made explicit and shared at the strategic level within local authorities. Our main research questions were:

- RQ1: How many children with an autism diagnosis are being looked-after by local authorities in England?
- RQ2: Is information about diagnostic status shared between stakeholders with corporate parenting responsibilities within the local authority?

A brief summary of the relevant and highly complex policy context is included below. This is not intended as a comprehensive overview, but rather an introduction to the key groups and terminology (in italics) that are central to this study.

Policy context for looked-after children in England

Numerous policies and legislative acts underpin and inform the statutory responsibilities of local authorities in England in meeting the needs of looked-after children (Department for Education, 2014, 2015; Department for Education/Department of Health, 2015a,b). The most pertinent are prescribed through the Children Act 1989, the Children and Families Act 2014 and the Children and Social Work Act 2017. The Department for Education (2015) makes it clear in its guidance on the Children Act 1989 that:

Assessing the needs of children and deciding how best to meet those needs is a fundamental part of social work with looked-after children. . . . The making of a care plan is central to these requirements. The care plan will contain information about how the child's current developmental needs will be met as well as the arrangements for the current and longer term care for the child. (paragraphs 2.1 & 2.2, p. 22)

As part of any plan, local authorities must provide a written health assessment of the child within a given timeframe. Guidance makes clear that the care plan must take due account of the particular needs of the child (Department for Education, 2015, paragraph 2.22, p. 27). CCGs are the main commissioners of health services and ' . . . should employ or have in place a contractual agreement to secure the expertise of Designated professionals, including *Designated professionals for Looked-After Children*. . . . The role is intended to be separate from any responsibilities for individual Looked-After Children, being a monitoring and quality assurance role rather than a managing one' (Royal College of Nursing, 2015, p. 2, our emphasis).

In addition to a health assessment, looked-after children are required to have a Personal Education Plan (PEP). Children with identified SEN may also have an EHC Plan that specifies the education, health and care services that the child or young person should receive. Guidance from the Department for Education (2015) makes it clear that the review of the PEP and, if relevant, the EHC Plan should be synchronised wherever possible.

To ensure that a young person's educational needs are met, all relevant schools (maintained schools, academies and free schools) must appoint a designated teacher for looked-after children. The designated teacher has lead responsibility for the development and implementation of the PEP within the school (Department for Children, Schools and Families, 2009) and should also liaise with the *virtual school head* (VSH). As defined in the Special Educational Needs and Disability Code of Practice: 0–25 Years (Department for Education/Department of Health, 2015a, p. 285), the VSH ' . . . is an officer of a local authority who leads a virtual school team that tracks the progress of children looked-after by the authority as if they attended a single school'.

Typically, the VSH and the designated teacher, designated health professionals as well as other senior local authority personnel will form the membership of a corporate

parenting board (CPB). According to the National Children's Bureau (2013, p. 2): 'Although not a statutory requirement, most local authorities have established a group of elected members to oversee the corporate parenting function of the local authority' in the form of a CPB or group. Thus, this group performs an important strategic function in ensuring that the corporate parenting requirements of local authorities are appropriately discharged for the vulnerable children in their care (see examples from Surrey County Council, 2010 and Birmingham City Council, 2015).

Methodology

The current study is part of the Autism Community Research Network @ Southampton (ACoRNS: <http://acornsnetwork.org.uk/>) initiative, which is an education-focused research-practice partnership between the University of Southampton (Education & Psychology Departments) and local schools/colleges across the ages and stages of compulsory education. One of the core principles of ACoRNS is that educationally relevant research questions should be driven, informed by and co-created with the practice and wider autism community in order to strengthen the connections between research and practice (Parsons *et al.*, 2013), and to ensure that the educational needs and priorities of autistic people and their families are at the heart of the research agenda. We deliberately use the term 'co-creation' to distinguish this model of researching and utilising knowledge from the more linear, traditional research models of knowledge transfer and knowledge exchange (Rynes *et al.*, 2001; Heinsch *et al.*, 2016). The current study was initiated from the community by a parent, one of the co-authors (AM), who had concerns about the extent to which looked-after children with an autism diagnosis were known to local authorities and their own experiences of the care system. AM gathered the data and we then worked together to interpret and discuss the data, as well as create this article.

Using freedom of information (FoI) requests as a source of social and healthcare research data is a 'very valuable' (Fowler *et al.*, 2013, p. 6), 'viable' (Walby & Larsen, 2012, p. 32) and 'powerful tool' (Savage & Hyde, 2014, p. 304) that can provide a '...unique perspective for scholars who are trying to conceptualize how government agencies work in action' (Walby & Larsen, 2012, p. 39). Keen (1992), writing within the US context, also noted how 'untapped' (p. 44) this mode of data procurement and production was; a sentiment echoed more recently by Walby and Larsen (2012) in Canada, and Savage and Hyde (2014) in the UK.

The Freedom of Information Act (2000) in the UK provided members of the general public with the right to request access to information held by public authorities, and similar rights have been enshrined in law internationally (see Lee, 2005). Individuals in the UK can do this by making FoI requests in writing, to which public authorities are obliged to respond in 20 working days (www.gov.uk, not dated). Therefore, as well as being a rich but underused source of data for systematic investigation (Walby & Larsen, 2012), accessing data through FoI requests also performs important democratic functions, both in terms of holding public authorities to account through making their workings more explicit and also through enabling wider participation of the public in research. In line with our co-construction values underpinning

research via the ACoRNS initiative, the use of FoI requests as a data collection tool is, therefore, highly appropriate, as Savage and Hyde (2014, p. 304) note:

... freedom of information has the potential to democratise the conduct of research beyond professional researchers by allowing a broader selection of the public to become engaged in research.

Ethics

Data produced by FoI requests 'will not pose ethical issues in the same way as research where data is gathered directly by the researcher, and should not need the same level of ethical approval as research where the data is generated by the researcher' (Savage & Hyde, 2014, p. 310). This is because there is a principle of the *right to access* information that is enshrined in the FoI legislation compared with a right *not to participate in research* which is fundamental to informed consent. Indeed:

The notion of ... FOI [sic] itself runs contrary to protective approaches to data. After all, it is only by invoking a legal right to know qua member of a public that ... FOI researchers are able to access backstage texts. (Walby & Larsen, 2012, p. 39)

Although there is awareness that data from FoI requests may not fit neatly into the traditional categories of primary or secondary data (Savage & Hyde, 2014), the data we solicited met the secondary data criteria for our own university research ethics review committee at the time of collection. Therefore, we did not require ethics approval to conduct this research via FoI requests, and we are not alone in reaching this conclusion (e.g. see Milligan *et al.*, 2011; cited in the systematic review by Fowler *et al.*, 2013).

Procedure

Between January and March 2017, FoI requests were sent by email to all English local authorities (county councils, unitary authorities, London and metropolitan boroughs, the Isles of Scilly and the City of London) via the heads of children's services, asking five main questions:

FoI1: How many children are looked-after by the local authority?

FoI2: How many children that are looked-after by the local authority have a diagnosis of autism (autism spectrum disorder, Asperger syndrome)?

FoI3: Has the designated health professional/clinical commissioning group ever reported to the corporate parenting board on the numbers and needs of looked-after children with an autism diagnosis?

FoI4: Has the virtual school head ever reported to the corporate parenting board on the numbers and needs of looked-after children with an autism diagnosis?

FoI5: Does the local authority have in place protocols to ensure that social workers and others (e.g. independent reviewing officers, virtual school heads, personal

assistants, carers) who support a looked-after child with autism are always aware of a child's autism diagnosis? If so, please provide details.

All responses were received via email and logged on a spreadsheet as they were returned. If no reply had been received after the statutory 20-day response period, a follow-up email was sent to the dedicated FoI email. The data collection period was closed after 3 months.

Findings

Numbers of looked-after children and looked-after children with autism

Table 1 provides an overview of the numbers of local authorities within each main region of England who responded and those who refused data or did not respond. Responses were received from 147 local authorities (a 97% response rate), though not always in full (see below). Note that while some local authorities refused to supply information relating to numbers of children (FoI1, 2), they nevertheless supplied answers to FoI3–5. Four did not respond at all within the 3-month data collection period; one response was received after this time, but too late to be included in the analysis. Of the 17 local authorities who withheld data, 9 gave a reason that disclosing the information could allow individuals to be identified when combined with other sources, therefore risking confidentiality, citing Section 40 exception (relating to personal data) and in some cases the Data Protection Act. Of these nine, the Isles of Scilly (South West) withheld all information, including the total number of looked-after children, citing a very low population that meant any disclosure could risk confidentiality. The remaining eight local authorities refused autism data because they did not hold the data centrally and a manual search would be required, which would exceed the upper limit of cost and time within the Freedom of Information Act search parameters.

Table 2 includes an overview of the data by region, showing the total number of children reported as being looked-after by the local authority as well as the numbers of children with an autism diagnosis, where this number was known. Some local

Table 1. Overview of numbers of responses within the English regions

Region	No response	Local authorities (responded)	Refused data	Full response	Data not held
London	0	33	4	25	4
South East	1	19	1	15	3
East	0	11	1	10	0
South West	2	14	2	10	2
West Midlands	0	14	0	13	1
East Midlands	0	8	1	7	0
North West	0	23	3	18	2
North East	1	10	2	8	0
Yorkshire & Humber	0	15	3	12	0
Totals	4	147	17	118	12

Table 2. Total number of looked-after children [LAC] and numbers, proportion and range of LAC with an autism diagnosis by region

Region	Total # LAC children ASD status known (total children)	# ASD LAC	% ASD diagnosis	% ASD range within regions		No. of authorities with <2% LAC with ASD	No of authorities with >5% LAC with ASD	# LAC children ASD status		Total # children
				Lowest	Highest			not known	known	
London	7,317	232	3.17%	0	8.8	7	5	2,734	10,051	
South East	7,409	288	3.89%	1.6	11	1	4	2,206	9,615	
South West	3,733	138	3.70%	2.1	7.2	0	4	1,203	4,936	
East	6,171	215	3.48%	1.1	5.6	2	2	266	6,437	
West Midlands	8,814	300	3.40%	0.5	12.7	7	2	580	9,394	
East Midlands	5,095	182	3.57%	1.2	5.9	2	2	43	5,138	
North West	11,130	226	2.03%	1.2	3.4	10	0	2,048	13,178	
North East	3,521	61	1.73%	0.8	3.8	6	0	709	4,230	
Yorkshire & Humber	6,263	146	2.33%	0	5.7	7	1	1,424	7,687	
Totals	59,453	1,788	3.01%	0.9	7.1	42	20	11,213	70,666	

authorities were able to give partial responses, that is, could say how many children were looked-after but not how many of these had an autism diagnosis. The remaining 118 local authorities gave a full response, classified as providing answers to FoI1, 2.

The proportion of children on the autism spectrum in Table 2 is calculated from the total number within each region where the numbers were known (the second and third columns). The total number of autistic looked-after children was 1,788 out of 59,453—an average proportion of 3%. The final column shows a higher number of looked-after children in total (70,666), but this includes the numbers of children within local authorities where the diagnostic status of children was not known or reported. Finally, Table 2 shows the number of authorities within each region for this category who had a relatively low percentage of looked-after children with an autism diagnosis (<2%) and those with a relatively high percentage (>5%) when compared to each other. As can be seen from these columns, there were 20 local authorities where the proportion of looked-after children with an autism diagnosis exceeded 5% and 42 local authorities where this proportion was less than 2%.

However, figures range from 1.7% in the North East, closely followed by the North West at 1.8% to 3.9% in the South East. It is also interesting to note the wide range of percentage ASD figures within each region. For example, the West Midlands ranges from 0.5%, well below the regional average of 3.4%, to 12.7%, much higher than the regional average. The overall range is from 0% ASD to 12.7% ASD of looked-after children in local authorities within England.

Report on children with autism to corporate parenting board from health professionals

FoI3 asked whether the designated health professional/CCG had ever reported to the CPB on the numbers and needs of looked-after children with an autism diagnosis. Responses were clear: of the 147 local authorities who responded, the majority (139; 94%) answered negatively. Eighty-three local authorities stated 'No', with no further information. Of those that did give more information, 11 restated the question with a negative response and 3 stated that they had not made a report because the CPB had not requested one. Eight stated that they did not hold the information centrally and five of these redirected the enquiry to another agency. Twenty local authorities made reference to the specificity of reports, that is, while reports had been made regarding children with SEN or EHC Plans, no report had been made that was specifically related to autism diagnoses. Ten refused to answer this question, mostly due to the time/cost of accessing the data or because they understood that the information had been published elsewhere. Only five authorities were able to answer positively, with a further two stating their plans to be able to do so in future.

Report on children with autism to corporate parenting board from virtual school head

FoI4 asked whether the VSH had ever reported to the CPB on the numbers and needs of looked-after children with an autism diagnosis. Again, responses were clear: of the 147 local authorities who did respond, 140 (95%) answered in the negative. Seventy-two local authorities simply answered 'No', with no additional information. Six local authorities refused to answer this question, either because they did not hold

the data ($n = 1$), the information was reasonably available elsewhere in published reports ($n = 2$; link to the data was provided), for data protection issues ($n = 1$) or the time/cost of accessing information to answer the question ($n = 1$). Additionally, one council refused to answer the question or provide information and has thus been classified as a refusal.

The remaining 'No' responses provided additional information. Thirty-five local authorities specifically referred to reports that were made to the CPB on children with SEND, EHC Plans or PEPs. Many of these authorities provided a regular report, annual or more frequent, on looked-after children with an EHC Plan, but reports did not include separation of type of diagnosis, although they would include those with an autism diagnosis. Thirteen further councils did not refer to SEND or EHC Plans but made reference to no 'specific' reports, that is, reports that were not specific to autism, or that no report specific to autism was made.

Only seven local authorities answered FoI4 positively, and this is with a generous interpretation of the data: three replied 'Yes' and attached a report; one replied 'Yes' but supplied no further information; two councils stated they had plans to report on this information in the future; and one responded that their reports included numbers of children with a SEN need diagnosed with autism and that the CPB members were able to ask questions at meetings.

Protocols for ensuring diagnostic status is known within multi-agency teams

FoI5 asked whether there were protocols in place to ensure that professionals supporting an autistic looked-after child were always aware of diagnostic status. If 'Yes', respondents were asked to provide further details, however, it was often difficult to compare responses to this question even when a definitive 'Yes/No' response was given, due to variations in interpretation of the question by the local authority. Many of the local authorities who answered 'Yes' used similar or less detailed procedures than some of those who answered 'No' or who did not answer either way but gave further detail. There was also considerable variation in the quality and detail of answers, which again made categorisation and analysis difficult.

Bearing these caveats in mind, 141 local authorities responded to this question. Sixty-one either stated 'Yes' or provided sufficient narrative details to demonstrate that policies and procedures were in place to ensure awareness of autism diagnoses. Eighty local authorities either responded 'No' or 'None', or were classed as a 'No' based on the information supplied, which suggested that it was unlikely that they had protocols in place to ensure everyone was aware of an autism diagnosis for a looked-after child.

The majority of local authorities referred to statutory assessments, plans and reviews regarding their policies and procedures. Multi-agency panels or reviews were also mentioned by several authorities. A few local authorities also mentioned having an 'Autism Strategy' or 'Autism Pathway' in place. Recording systems were often cited, including electronic systems. Some councils referred to specialist teams or professionals and some had a focus on training and support. A common response was that there was not an autism-specific protocol but that the systems used for all looked-after children or those with SEND would apply to those with autism and in

effect ensure that everyone who needed to know would do so. However, a small number felt that health information could not be shared with schools and others without parental/carer consent, or that it was the parent/carer's responsibility to ensure those who needed to know did so.

Discussion

The aim of the present study was to use a novel (for the field) and unbiased data collection approach, FoI request, to collate the data on the number of autistic children in the care system in England. Our study found that there are approximately 3% of looked-after children formally recorded as having an autism spectrum diagnosis in England: nearly 1,800 children. This is more than the number reported by the Department for Education (2017a), likely due to categorisation differences, but is still an underestimation of the true picture, as some local authorities did not respond to our FoI request or refused to supply relevant data. Moreover, the high proportion of (previously undiagnosed) autistic features in adopted children reported by Green *et al.* (2016) further suggests that the actual numbers of autistic children in care are likely to be higher than the 3% we report here.

This conclusion is also supported by the wide range in the proportion of children on the autism spectrum within each region, and between local authorities, as well as the many local authorities reporting lower than average percentages of looked-after autistic children compared to those with higher numbers. Moreover, there is an indication of a North/South divide in the number of looked-after children with autism diagnoses, with higher proportions being reported in the South and lower proportions in the North. These wide ranges warrant further investigation to ascertain the reasons for the differences. Certainly, significant variation exists across local authorities in England with respect to the numbers of children identified as needing EHC Plans (Marsh, 2018). There is also wide variation across the UK in relation to experiences of the diagnostic process for parents (Crane *et al.*, 2016) and professionals (Rogers *et al.*, 2016). In addition, complex intersections exist between socioeconomic status, maternal level of education and rates of autism diagnosis, showing that mothers with higher levels of education had twice the rate of autism diagnosis amongst their children compared to mothers with lower levels of education (Kelly *et al.*, 2017). It is already well established that material deprivation, and low educational attainment, intersect with SEN and the looked-after status of children (Department for Education, 2018b), and that the effective marshalling of resources by families plays an important role in identification and support (House of Commons, 2006; Daniels & Porter, 2007). Further, as already noted in the Introduction, there are also challenges relating to differential diagnosis amongst children in care (e.g. DeJong, 2010). Nevertheless, while the reasons for the range in known diagnoses are likely to be complex, these findings should provide important indications to local authorities that there is a need to investigate local systems and practices for assessment and diagnosis.

Notwithstanding the probable underestimation of numbers in the present study, there is still a significant number of autistic children for whom the local authority has

corporate parenting responsibilities. It is therefore surprising and concerning that this study shows that specific diagnostic status is not a characteristic of looked-after children that is routinely shared, prioritised or acknowledged at a strategic level within most local authorities in England. This is despite the recommendations from Sebba *et al.* (2015, p. 7) that ‘sufficient account’ should be taken of such characteristics and from Selwyn *et al.* (2014) that local authorities should ensure appropriate services are available for children on the autism spectrum specifically. Moreover, it is clear from the Department for Education’s (2013, p. 9) guidance for directors and lead members of children’s services that they have statutory responsibilities to ‘support the drive for high educational standards for all children and young people, paying particular attention to the most disadvantaged groups’. We would argue that autistic children are one of the most disadvantaged groups who require particular attention in this context.

While the implications of this lack of shared or prioritised knowledge at the strategic level are difficult to judge from this study, these findings nevertheless raise some important further questions about whether and how diagnostic status is appropriately monitored by CPBs when planning for, and overseeing, children’s placements, development and progress. Green *et al.* (2016, p. 1400) highlight that there are ‘immediate and significant’ implications for practice in identifying autistic children within the care system ‘...since identification of ASD impairments has specific implications for family understanding, style of intervention, and educational planning’. As a corollary, if those with corporate parenting responsibilities within local authorities are not sufficiently aware of autistic children’s current developmental needs, then it is unclear how strategic educational planning can most effectively meet those needs. Our findings, coupled with the evidence from Selwyn *et al.* (2014), Sebba *et al.* (2015) and Lenehan (2017), suggest that there would be value in highlighting autism diagnostic status as a strategic flag for monitoring provision, progress and outcomes, with improvements included in objectives as a strategic priority.

Although there is debate in the literature about the most effective ways of improving government services (Rashman & Radnor, 2005), there is also good evidence that rational planning—the setting and monitoring of targets—can have positive impacts on performance. For example, Boyne and Chen (2006) analysed data from 147 local authorities in England in relation to targets for educational performance at Key Stage 4. Those local authorities with specific indicators for improving exam performance achieved higher scores than those without a target. Similarly, Matthews and Sammons (2005) demonstrated that schools in special measures following OfSTED inspections often improved more than others with less serious concerns, at least partly due to more intensive monitoring of targets for improvement and related support. Sloper (2004) further provides evidence that the regular monitoring and evaluation of policies and procedures can support successful multi-agency working, though also illustrates that this is just one of many factors that need to be addressed in order to facilitate effective collaboration and coordination of service provision. Nevertheless, as Tilbury (2004, p. 227) argues, performance indicators can have positive effects because they help to define and shape policy by directing resources and actions towards priority areas, thereby ‘allocating power amongst policy perspectives’. We suggest that,

as a very vulnerable and disempowered group of young people, autistic looked-after children could benefit from such an allocation of power in the strategic acknowledgement and monitoring of their specific needs.

At the moment, such monitoring at the strategic level does not seem to be the case, but even simply asking the question has placed a (potentially uncomfortable) spotlight on this area within some local authorities. There were a number of emails received in response to the FoI requests, including one from a director of children's services and one from a VSH, which indicated that the FoI request itself had identified issues with strategic reporting and would lead to change. Indeed, as emphasised in the recent guidance from the Department for Education (2018c), the VSH should play a vital role here, since 'For looked-after children, as part of a local authority's corporate parent role, the VSH needs to be the educational advocate that parents are for others' (p. 5). Our hope is that this article casts a wider light, at a systemic level, onto this important issue and may lead to further changes.

We end this section with a comment from the parent who initiated this study:

The responses raise fundamental questions about what is happening on the ground to ensure autistic looked-after children and their carers are given support that is 'right first time' for them. This should be very unsettling for anyone with a duty to provide good care for looked-after children. [Nevertheless] it was clear from the honesty of many of the responses that, for many, loyalties lay with vulnerable children. It is these answers, that identify their own difficulties honestly, that give me hope.

Strengths, limitations and further research

As an underused methodology, it is important to reflect on our experiences of using FoI requests to obtain data from public authorities in a systematic way. In terms of strengths, it is evident that we achieved a very high response rate, which is much more favourable than traditional survey methods (Fowler *et al.*, 2013), thereby providing good representativeness and, hence, external validity. The reliability of (at least some of) the information supplied can also be checked via triangulation with other sources. The total number of children reported as looked-after via these FoI requests shows reasonable alignment with other published data (Department for Education, 2017a), notwithstanding the categorisation differences, thereby providing some confidence that the data were accurate. Overall, in line with others who have used this approach (Keen, 1992; Lee, 2005; Fowler *et al.*, 2013; Walby & Larsen, 2012; Savage & Hyde, 2014), we think that this is a powerful means of providing a systematic snapshot of local authorities in action, at least at the strategic level.

However, data can only ever be partial and responses depend on who receives the request and prepares the information (Walby & Larsen, 2012). The quality of the data also depends on the wording of the questions, as is the case with any other social research methodology. Certainly, in relation to FoI5, there was more uncertainty over its interpretation and responses, suggesting that some follow-up is needed. Such a study could use structured sub-questions and less ambiguous phrasing to allow comparisons to be made more easily. Since a FoI request is likely to be answered by someone outside of social services and looked-after children's services, these

questions should ideally be sent to an identified professional involved in the care of looked-after children.

Inevitably, only a surface snapshot of information sharing was provided; there is clearly much more to find out. More in-depth enquiries would be valuable, including interviews with all relevant stakeholders, especially young people and families/carers. It is acknowledged that many families in this context are likely to feel marginalised and alienated, such that building trust in order to share views will be a complex and timely, though essential, process (Boag-Munroe & Evangelou, 2012). Targeting the designated professionals and VSHs for follow-up would certainly be beneficial, particularly in those small number of local authorities where positive responses were indicated. In addition, exploring in more detail the specific practices around mandated policies and procedures, including the use of the Pupil Premium Plus (Department for Education, 2018c) and PEPS (e.g. see Parker, 2017) will be important. Being able to identify and illuminate good practice from a range of perspectives would be a very insightful next step.

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NOTE

¹ In line with the preferences of the UK autism community, the terms ‘on the autism spectrum’ or ‘autistic person’ will be used rather than ‘person with autism’ to represent identity-first language; for further discussion, see Kenny *et al.* (2016).

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