



Awareness within local authorities of autism spectrum diagnoses of Looked-After children in England

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What is the issue?

There are over 100,000 children at school in England with Autism Spectrum Disorder (ASD) as their primary identified need¹, and we are gradually finding out more about their experiences through education-based research². However, much less is known about children with ASD who are Looked-After by their local authority. There is cause for concern following the findings of Fletcher, Strand and Thomas (2015)³ who reported that the academic outcomes at GCSE for Looked-After children with ASD were much poorer than for children with ASD who were not Looked-After by their local authority. The aim of this project was to generate an up-to-date snapshot of the numbers of children who were recorded as having a diagnosis of ASD and being Looked-After by local authorities in England, and to assess how aware relevant local authority stakeholders were of their diagnostic status and needs at a strategic level.

What did we do?

Between January –March 2017 Freedom of Information (Fol) requests were sent to 151 local authorities in England, asking five main questions about the numbers of autistic children being Looked-After, and whether these numbers, and children's needs, are reported and monitored at a strategic level within the local authority. This project was initiated by the first author, Alice McCullen, a parent who had concerns about the extent to which Looked-After children with ASD were known to local authorities, and their own experiences of the care system. Tracey Emery, under the supervision of Professor Sarah Parsons and Dr. Hanna Kovshoff at the University of Southampton, and working under the ACoRNS remit for community generated research, completed a thorough analysis of the data during the summer of 2017. Key information obtained from each of the Fol questions is summarised below.

¹ Department for Education (2017) [Special educational needs in England: January 2017](#)

² Fayette, R., & Bond, C. (2017). [A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences](#). *European Journal of Special Needs Education* (in press).

³ Fletcher, J., Strand, S. & Thomas, S. (2015) [The Educational Progress of Looked After Children in England Technical Report 1: Secondary School Progress and Attainment](#).

What did we ask and what did we find out?

- 1: How many children are Looked-After by the Local Authority?
- 2: How many children that are Looked-After by the Local Authority have a diagnosis of autism (Autism Spectrum Disorder, Asperger Syndrome)?

Of the 151 local authorities who were contacted in England, 4 did not respond. Of the 147 who responded, 17 refused information regarding autism diagnosis and 12 claimed the data were not held. The remaining 118 local authorities gave a full response.

In total, 70,666 children and young people were recorded and reported as being Looked-After by the local authority. 59,453 looked after children lived in councils where the ASD status was known and disclosed (84.1%). **Of these, 1788 (3.0%) children were recorded as having an ASD diagnosis.** A further 11,213 children were Looked-After in councils that did not have or did not disclose the numbers of children with autism (15.9%). **Therefore, the 3% figure of children with ASD is very likely to be an underestimation.**

- 3: 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?

Out of the 147 who provided a response, only five local authorities were able to answer this question positively, with two stating their plans to be able to do so in future. The majority (n=139) answered in the negative:

- 83 local authorities simply stated “No” with no further information;
- Of those that did give more information, 11 councils simply restated the question with a negative response and 3 councils stated they had not made a report because the Corporate Parenting Board had not requested one;
- 10 refused to answer question 3 mostly due to the time/cost of accessing the data or since the information had been published elsewhere and therefore could be reasonably established;
- 8 councils stated that they did not hold the information centrally and 5 of these redirected the enquiry to another department;
- 20 local authorities’ responses made reference to lack of specificity of reports, that is, no report had been made that was specifically related to autism diagnoses.

- 4: 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?

Of the 147 local authorities who responded, the majority (140; 95%) answered this question in the negative. This means that the majority of local authorities’ Virtual School Heads have never reported to the Corporate Parenting Board on the numbers and needs of Looked-After children with an ASD diagnosis. Some responses indicated that this would be inappropriate due to confidential information being included in a public report and associated risk of identifying individuals.

5a: 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?

5b. If so, please provide details.

141 local authorities responded to this question. **61 either stated “yes” or provided sufficient narrative details to demonstrate that policies and procedures were in place** to ensure awareness of diagnosis. **80 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. In addition:

- The majority of local authorities referred to Statutory Assessments, Plans and Reviews regarding the policies and procedures they had in place. Multi-agency panels or reviews were also mentioned by several authorities.
- 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 special educational needs and disabilities 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 education and others without parental consent, or that it was the parent's responsibility to ensure those who needed to know did so.

Implications for practice and research

1. The total numbers of children reported as Looked-After shows good alignment with other published data⁴ and so this snapshot via FoI requests shows high validity.
2. On average, 3% of children and young people being Looked-After in England are known to have an ASD diagnosis; higher than the 1-2% prevalence rate of ASD in the general population in the UK.^{5 6} The reasons for this elevated level need to be further researched and better understood. However, it is also likely that this is an underrepresentation of the actual numbers due to the failure of some local authorities to supply this data, and evidence from other studies showing a high level of ASD features in children within the care system⁷.
3. It is clear that ASD status is not a category of need that is reported or monitored at a strategic level within most local authorities. This raises important questions about the extent to which the specific needs of those with ASD being Looked-After are appropriately acknowledged and met.
4. There was significant variation in the quality and depth of responses given to question 5. Many of the local authorities who replied “no” to this question referred to the same kinds of assessments, plans, reviews and meetings as those who responded “yes”. It is therefore likely that the data at least partially reflects differences in interpretation of the question. A follow-up study could use structured sub-questions to more accurately probe existing processes and procedures.

⁴ Department for Education (2017) [Children looked after in England including adoption: 2016-2017](#)

⁵ Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368(9531), 210-215.

⁶ Russell, G., Rodgers, L. R., Ukoumunne, O. C., & Ford, T. (2014). Prevalence of parent-reported ASD and ADHD in the UK: findings from the Millennium Cohort Study. *Journal of Autism and Developmental Disorders*, 44(1), 31-40.

⁷ Green, J., Leadbitter, K., Kay, C., & Sharma, K. (2016). Autism spectrum disorder in children adopted after early care breakdown. *Journal of Autism and Developmental Disorders*, 46(4), 1392-1402.