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# Educational Provision for Girls with high functioning Autism

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## Is there a gender difference?

Recent research has indicated that there is a divergence according to gender within the core symptoms of Autism Spectrum Conditions (Baggiato et al., 2016). The research from the University College London and the Institute of Child Health concluded:

*“The factors underlying this predominance of males are largely unknown, but the way girls score on the standardised categorical diagnostic tools might account for the under recognition of ASD In girls.... Despite the existence of **different norms** for boys and girls with ASD on several major screening tests, the algorithm of the Autism Diagnosis Interview-Revised (ADI-R) has not been reformulated.... **The potential gender bias thus induced may participate in the under estimation of the prevalence of ASD in females**”*

*Baggiato et al., (2016)*



The above research confirms the American findings of Hiller et al. (2014) who also explored the attitude of teachers towards girls with ASCs:

*“Teachers reported substantially **fewer concerns for girls** than boys, including externalising behaviours and social skills. Results suggest **girls with ASD may present with a surface-level ‘look’ different from the ‘classic’ presentation of ASD** and present as less impaired when in a school setting.”*

Additional research from Frazier & Hardan (2016) and Hull et al. (2016) also confirm such gender differences within ASCs, whilst Mussey (2017) highlights those factors that vary within gender as predictors of the severity of ASC, rather than between.

## Why is this important?

The above research from the Centre for Research in Autism and Education (Bargiela et al., 2016) not only identifies these differences but also outlines their impact:

*“gender led various professionals **to miss** their ASD; and of conflicts between ASC and a **traditional feminine identity**”*

Moreover, this research explicitly demonstrates that:

*“experiences of **sexual abuse were widespread** in this sample, partially reflecting specific vulnerabilities from being a female with undiagnosed ASC.... **Training would improve teachers’ and clinicians’ recognition of ASC in females**, so that timely identification can mitigate risks and promote wellbeing of girls and women on the spectrum”*  
(Bargiela et al., 2016)



Given the above challenges regarding the identification and diagnosis of ASC in girls, it is important to understand how these issues present themselves from a qualitative perspective both at the individual level and how they affect the family. It would be useful to explore the **‘individual journey’** rather than adopt a quantitative framework in order to maximise the ecological validity of the female experience of an ASC. **Examining individual case studies allows a detailed qualitative understanding which may better address the adequacy of the educational landscape for girls. It would better illuminate their difficulties from both an education and health service user perspective; and would present an opportunity to consider the strengths and weaknesses of the educational response towards females who exhibit an ASC.**

## **What does the journey to diagnosis, educational provision and health care look like for a girls with an ASC?**

### **The National Picture**

From both a personal perspective and as a parental supporter to over 50 parents of children with SEND (particularly high-functioning ASC girls) I believe mainstream schools are ill-educated, ill trained and ill-equipped to assist with the identification of ASC. Females with ACS are more likely to be viewed as exhibiting ‘naughty behaviour’ often attributed to ‘poor parenting’, or ‘mental health’ issues. **Teachers require urgent training in ASC to ensure earlier identification.** From a legislative perspective, schools **do not routinely follow the SEN Code of Practice** to ensure that needs are effectively identified and often adopt a culture of ‘parental blame’ which may delay the identification of an ASC. CAMHS professionals may also adopt the same approach which may cause further delay on the journey to diagnosis.

**This may result in unwarranted child protection referrals and the removal of children from their families in closed courts where the same professionals may ‘miss’ the female presentation of an ASC by misdiagnosing an ‘attachment disorder’.** In LAs and CCGs who refuse to acknowledge those parts of the spectrum that exhibit less variation between gender, such as **Pathological Demand Avoidance (PDA)**, this adds to the postcode lottery experience for **Autistic girls.** The situation usually escalates to Tribunal as parents attempt to ensure that the needs of the child are correctly identified and subsequently, met. It is at this point, that the situation usually becomes an adversarial process.

On a national level, evidence suggests that LAs **do not typically want to perform statutory needs assessments** - perhaps because of the long term costs associated with supporting an ASC child.

This is a battle most often fought in Tribunal where the vast majority of families, fortunately, are successful. In the event that the LA does not force the parent to Tribunal for an assessment and the family avoids a Tribunal, the LA does not typically conduct any formal assessments nor quantifies and specifies the provision and the underlying diagnoses continues to be missed - resulting in inappropriate provision within the EHCP. In the event of an appeal concerning provision, the LA *only then* wants to formally 're-assess' the child and **the LA response is to attempt to perform the assessments they should have conducted during the needs assessment process; Please note it is not within Tribunal's remit to reinstate the responsibility of the LA to perform the assessments they should have already conducted.** If the parent refuses these LA assessments, the LA then typically applies to SENDIST for a court order for access to the child. It is of interest that recent SENDIST data from Jane McConnell, Head of SENDIST, indicates that the Tribunal system is completely over-run and there are many parents in poorly performing LAs that are on **repeat cycle to Tribunal at great expense to both tax payers and families alike.** Sadly, when the SENDIST process has been exhausted, the irony is that SENDIST has no jurisdiction to ensure their decision is enforced and the only right of challenge available to parents is the use of Judicial Review at even further expense. During the course of this process, children may spend long periods of time outside education, despite the child's right to receive an education under the Education Act (1996) and an existing EHCP (Child & Family Act, 2014).

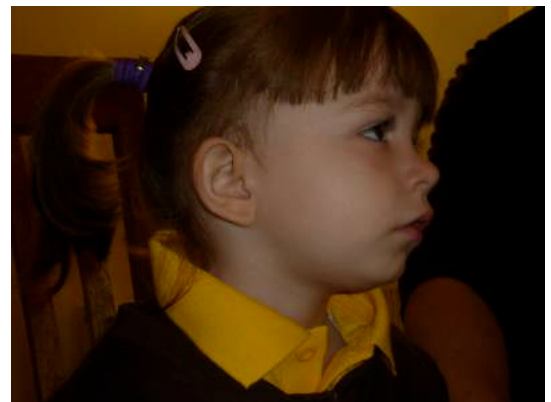


The remit of SENDIST is not concerned with the ongoing stress to families from an emotional and financial perspective. However, parents are likely to become full-time carers during this period which further places the family under stress because they are stuck in a process they are not in control of. Unfortunately, this has the capacity to effect the 'carer's wellbeing' due to the perceived loss of 'loci of control' causing anxiety and depression via the well established theory of 'learned helplessness' (1967, Seligman). However, SENDIST is the only mechanism available to ensure that the child's needs are met and parents endure this process because there is simply no other alternative. Such learned helplessness could further be reinforced by caring full time for a child with very complex needs or possibly by the lack of access to mental health services should an undiagnosed ASC have effected the child's mental health. In the event a diagnosis of ASC has been determined, any co-morbid mental health conditions are likely to be left untreated due to the umbrella, Autism diagnosis. At this point, the parent is firmly entrenched in a position they are simply not in control of which does not allow for the fact that the parent usually knows their child best. This is a scenario detrimental to parents' own mental health due to their perceived loss of control. This assumes of course, that the family has not already given up fighting a broken system, has run out of money or has simply opted to Electively Home Educate the child because the battle appears insurmountable. **On a national scale, I believe that many children with an ASC are being forced into Elective Home Education due to the difficulty in negotiating the existing process.** To assume that SENDIST is a parent-friendly route of challenge and one in which the parent is capable of representing themselves against an LA barrister, supported by solicitor sitting in a corridor at SENDIST is a fundamental misconception - only those with deep pockets, resilience and stoicism will succeed within this adversarial system.

As children with an ASC are more likely to be the subject of Tribunal proceedings, the above challenges are clearly not restricted nor localised to girls with an ASC. **However, what is unique to girls in the current climate is that they are more likely to be the subject of highly complicated cases simply due to the difficulty of diagnosis and this is further compounded by the lack of placements available. They are clearly an ‘at risk’ group.** They are more likely to be subject to discrimination when having their needs identified and therefore, less likely to achieve positive outcomes due to their needs being missed for many years until they arrive in the CAMHS system with mental health needs. A different approach is clearly required in order to better understand how girls are coping within a system that does not readily recognise their ASC. It is my belief that this can only be achieved by adopting a case study approach.

## The case study perspective

During our five-year battle to secure educational provision for my daughter, we have engaged with Nigel Thompson (CQC SEN Inspection Lead), Sean Harford (National Director of OFSTED) and Stuart Miller (Deputy Director of SEN at the DFE). It has been Nigel Thompson of the CQC who has been most helpful, directing us to people such as Teresa Joyce (Mental Health Advisor for the CQC) who - during one discussion mid tribunal - described our case as the **‘educational equivalent of LB’** and anticipated that our particular case runs the risk of becoming a **‘serious case review’**. Unfortunately, it is to the significant detriment of the child that an LA usually ignores mental health advice, becoming an **institutional safeguarding issue for the child. This is clearly a scenario that has developed via the lack of accountability within the LA. Alternatively, it may even be the case that the LA attempts to persuade NHS mental health professionals to follow the LA agenda.** Regardless, case studies such as this that have been raised at national levels **must** be examined in order to provide due diligence of the SEN system. Such cases are especially relevant in those LAs recently identified as performing poorly such as SurreyCC or Sefton MBC. Of particular interest should be cases of an ASC/PDA profile where local CAMHS practitioners acknowledge that this profile is usually accompanied by a significant history of child protection involvement. **It is of critical importance that these parents are not viewed as ‘agitators’ - as described by Edward Simpson (MP) - but as opportunities to identify what is going wrong for girls with ASC** (<https://www.specialneedsjungle.com/send-superheroes-ready-spruce-school-provision/>).



With particular reference to ASC diagnosis in girls, it is the national issues described above that are leaving girls without an appropriate diagnosis via the statutory assessment process. With specific reference to our case, **this resulted in my daughter being forced four times into mainstream schools which led to repeated failures that significantly affected her mental health, created challenging behaviour and ultimately culminated in repetitive behaviour for nearly twenty hours a day.** Despite an existing EHCP for complex need, this was dismissed in writing as ‘parental failure’ and a ‘behavioural problem’ by a diagnostic nurse at a flagship children’s hospital and **access to emergency mental health services was denied. This reflects the wider lack of joint commissioning of services for children with highly complex needs already identified as being**

**problematic in some LAs during SEN inspection.** This then, forced us into private psychiatric care where the ASC was again missed, with comments such as, '*she is clearly a very disturbed child*', until we finally requested that the Lorna Wing Centre (part of the National Autistic Society) with a specialisation in female diagnosis) assess my daughter for an ASC. The cost of which would have been beyond the reach of many parents. My daughter's Autism was eventually diagnosed after five years (after missed/misdiagnosis by over twenty professionals ranging from EPs, SALTs, Paediatric specialists and CAMHS professionals) at the cost to her mental health whilst being denied access to an education and NHS mental health services. **It is not true that once an EHCP is in place, the child's educational and health needs are addressed; there is a distinct lack of accountability within local government to ensure that any existing EHCP is delivered nor access to health services is provided.** Such is the reality for all children with an ASC as it stands today but this is of particular relevance to girls.

Once a diagnosis had been finally obtained, it could be assumed that this would result in appropriate provision being put in place; this is sadly not the case. It is only then that the real battle commences against the LA for appropriate provision. In our case, this battle resulted in **another year of missed education** whilst awaiting Tribunal, where the only objective of the LA - even during the Tribunal hearing - was to delay the process of providing education by requesting an adjournment. Requests via Stuart Miller to the DFE for intervention prior to Tribunal were largely unheard and the response from department advisors was that, '**it takes time for an LA to secure a school**'. It is indisputable that there is a shortage of appropriate placements for high functioning girls with an ASC diagnosis, especially one with a profile that could be described as being 'demand avoidant'. Despite this, we were forced into the Tribunal system even though the LA had no evidence to present, no case and had named no placement. This was a delaying tactic which persisted right up until the day of the hearing where the LA requested an adjournment (thankfully, denied) during the hearing via their barrister. It is of further interest that a week prior to Tribunal, the provision the LA had agreed to specify in Section I, received an advice notice as operating an illegal school and there are children within that setting still not receiving their legal entitlement to a full time education.

The entire process to secure educational provision **through out this year alone cost us somewhere in the regions of thirty thousand pounds.** And in Jan'17, we were forced to pay for our own education assessment placement at the cost of an additional, **nine thousand pounds.** Our case should never have reached Tribunal, the LA provided one page of evidence in the form of an email and those who attended the Tribunal had never met my daughter. The CQC, OFSTED and the DFE were all kept up to speed through out the entire case creating an unprecedented paper trail.

In extremely complex cases such as this where the Tribunal is satisfied that the best course of action is to stipulate **EOTAS (Education Other Than at School)** in Sec I of an EHCP, there is only one appropriate course of action, which is the use of a Personal Budget to deliver the provision specified in Sec F. Unfortunately, however there is no law that can force a LA to use a Personal Budget and it is at this point that many children are forced within the low-cost, LA complementary education service (who may or may not be well equipped to meet the complex needs of children with a ASC). It is undeniable that for some children, EOTAS delivered via a personal budget is the most appropriate course of action. Against the growing numbers of children sitting outside education, this is clearly the preferable option although seldom used.

## Conclusion

The recent commentary from **Professor Baron-Cohen highlights the urgent need to address the human rights of these children that are currently being violated.** As demonstrated above, such issues are more likely to effect girls due to difficulties with diagnosis and the failures that already exist with the SEN process creating the perfect storm. The case study presented above is neither isolated, localised and it is certainly not an outlier within the educational and health care system as it stands today. The current system is one of adversarial chaos within which most parents without the necessary determination, resilience and deep pockets are pushed outside of realms of education and most parents in my experience give up and choose Elective Home Education. **The situation requires urgent review with special attention given to girls on the spectrum.**



The current challenge for LAs is undoubtedly clear. **Parents will continue to challenge LAs to ensure that they apply the law and not their policies.** It is my fundamental belief that the wrong question is being asked here at Parliament today. The question remains, why is there so little accountability and challenge from central government to LAs? And what assurances can central government provide to those parents who do not have the necessary resilience and determination to ensure that the human rights of these children are upheld within a system that does not necessarily preoccupy itself with the **'best interests of the child'**.