

FOCUS GROUP REPORT

# Autism and Girls In Northumberland

Aug 21

## Introduction

The focus group was established following concern raised by the North Northumberland Autistic Society (NAS) Branch through the Northumberland Parent Carer Forum, that girls and Autism represented an area of unmet need. Informal discussion with practitioners identified similar concerns, with practitioners feeling that girls and Autism appear 'more prevalent' with apparent increasing presentations of anxiety, school refusal, gender dysphoria and eating disorders in those on diagnostic pathways or with a diagnosis.

## Methodology

A focus group was established with representatives from a wide range of partners including Parents and Carers, North Northumberland National Autistic Society, Toby Henderson Trust, Northumberland CCG, Northumberland County Council, Northumbria Healthcare NHS Foundation Trust and Cumbria Northumberland Tyne and Wear NHS Foundation Trust. See appendix 1 for a full list of contributors.

The focus group identified the following aims

1. To establish a snapshot of data and information about girls and Autism from all parts of the system
2. To review information and identify actions that could be taken to improve identification of girls with Autism from within existing resources

It was agreed the group would be time limited and would produce a written report for the Autumn Term 2021 which would be shared at the SEND Strategic Partnership and the Autism Partnership Boards. The group met a total of four times, with smaller groups meeting around particular issues or areas.

## Experience of parents and carers

Information was provided through the following

- North Northumberland Autistic Society identified themes from families who sought their support between September and December 2020
- 27 parents and carers met with Sam Barron, Strategic Lead for SEND in February 2021 in a session facilitated by the North Northumberland Autistic Society to share their experiences

The following themes and issues were highlighted.

Social, emotional and mental health of children and young people

- High anxiety, especially during the pandemic and dark thoughts
- Eating disorders / fussy eating
- Anxiety leading to self harm
- Not feeling comfortable or fitting in, particularly around transition
- Losing social skills during lockdown and terror of going out again.
- Tiredness and exhaustion spiralling into anxiety
- Depression

#### Social, emotional and mental health of parents and carers

- Parents reporting feeling exhausted in managing the system and interacting with practitioners
- Parents reporting they don't feel practitioners believe them and there is a need to repeatedly explain themselves, particularly when there is a difference in how their child presents at home from at school
- Onset of puberty, alongside a change of school increases anxiety leading to reaching crisis points as children become older
- Several parents have given up work to look after their child, which impacts on financial and emotional wellbeing

#### School and support for learning

- Children refusing to attend school, particularly as they get older
- Significant problems with transition especially to secondary school
- Parents reported educational provision for high functioning girls or those who would benefit from learning in smaller groups is lacking
- Lack of confidence in the commitment of mainstream educational provision at secondary level in the north of the county to be inclusive, make reasonable adjustments and work with parents and young people to support transition and provide effective support and teaching for their children
- EHCP's being refused but often awarded after appeal

#### Diagnostic pathway

- Difficulties receiving a diagnosis for a variety of reasons, school not always seeing the behaviours/anxiety or having enough evidence, appearing to be managing academically, quiet and not disruptive, family not being believed – different reasons being given for the anxiety sometimes relating to health of other members of the family (ie child stressed because parents are stressed)
- Discussion around the diagnostic testing and questions asked to girls eg “ Do you have friends at school?” Parents reported a typical answer to this question from their daughters was “Yes”. But if asked if they miss their friends would answer “ No I'm not interested in keeping in touch.” Perception that diagnostic questions relate to boys and that girls can manipulate the answers so that they are replying how they think the questioner wishes them to do so.

- Many teachers, practitioners and parents are unaware of the difference between boys and girls and their presentation.
- Diagnosis given but then no help
- When diagnosis has been early families reported their daughters are easier to look after as teenagers and many girls are happier with who they are

#### Support for health concerns

- Several parents reported that when they sought support for other health issues eg toileting, it was difficult to obtain support as any additional health concern was treated as if it was associated the AUTISM diagnosis and was therefore not available for treatment
- Some families were referred back to CYPS several months after diagnosis for support for mental health

## Data : Autism and Girls

Northumberland SEND Strategy 2021-24 sets out the following ways that progress would be monitored around improving outcomes.

	<b>Listening</b> – to children, young people and their families to understand how we are making a difference and what we might need to change.
	<b>Practice</b> – look at how well we deliver support and services to children, young people and families.
	<b>Data</b> – look at what activity we do and how it compares to others

The following is the data collected from different parts of the system and references which elements of improving outcomes the data addresses.

### [Northumberland Inclusive Education Services \(NIES\), Autism Support Service, NCC](#)



The Autism Support Team offer school based support to children and young people in Northumberland with social communication difficulties or a diagnosis of Autism. The Service aims to develop and enhance the skills and practices of school staff and improve educational outcomes for children and young people with social communication/autism needs in educational settings across Northumberland.

*Data provided* : number of boys / girls referred to the team by schools

*Data limitations* : For the years 2017-18 and 2018-19 the service was funded through a Service Level Agreement funded by the school the child attended. For these two

years, the data therefore reflects the schools ability to fund the support rather than reflect the level of need that is available. From 2019-20, the support was free at point of delivery and will be more representative of need for support.

Referrals to Northumberland Inclusive Education Services – ASD Team, NCC						
Boys / Girls	North	Central	South East	West	Other	Total
17-18	72 20 78% 22%	69 18 79% 21%	86 14 86% 14%	39 13 75% 25%	1 0 100% 0%	267 65 80% 20%
18-19	69 38 64% 36%	80 15 84% 16%	66 16 80% 20%	35 20 64% 36%	0 0	250 89 74% 26%
19-20	56 38 63% 37%	49 16 75% 25%	83 25 80% 20%	17 15 53% 47%	2 0 100% 0%	207 94 67% 33%
TOTAL	197 96 67% 33%	198 49 80% 20%	235 55 81% 19%	91 48 65% 35%	3 0 100% 0	724 248 74% 26%

#### Analysis

- Greatest proportion of referrals for girls are in the West > North > Central > South East
- Proportion of girls has increased overall over the past three years
- Referrals to service decreased over the last three years. This is likely to be due to the fact that the service was delivered via a service level agreement which schools funded from their budgets (NB the SLA is no longer in place and the service is now free at point of delivery)
- Sept 20 onwards – highest referrals per head of population and highest percentage of girls referred in North

#### EOTAS (Education Other Than At School), NCC



The EOTAS Health Needs team provides for learners who are of statutory school age but who are unable to attend school full time due to **health and medical needs**. Tuition is provided on a one to one basis or in small groups depending on the needs of each individual pupil.

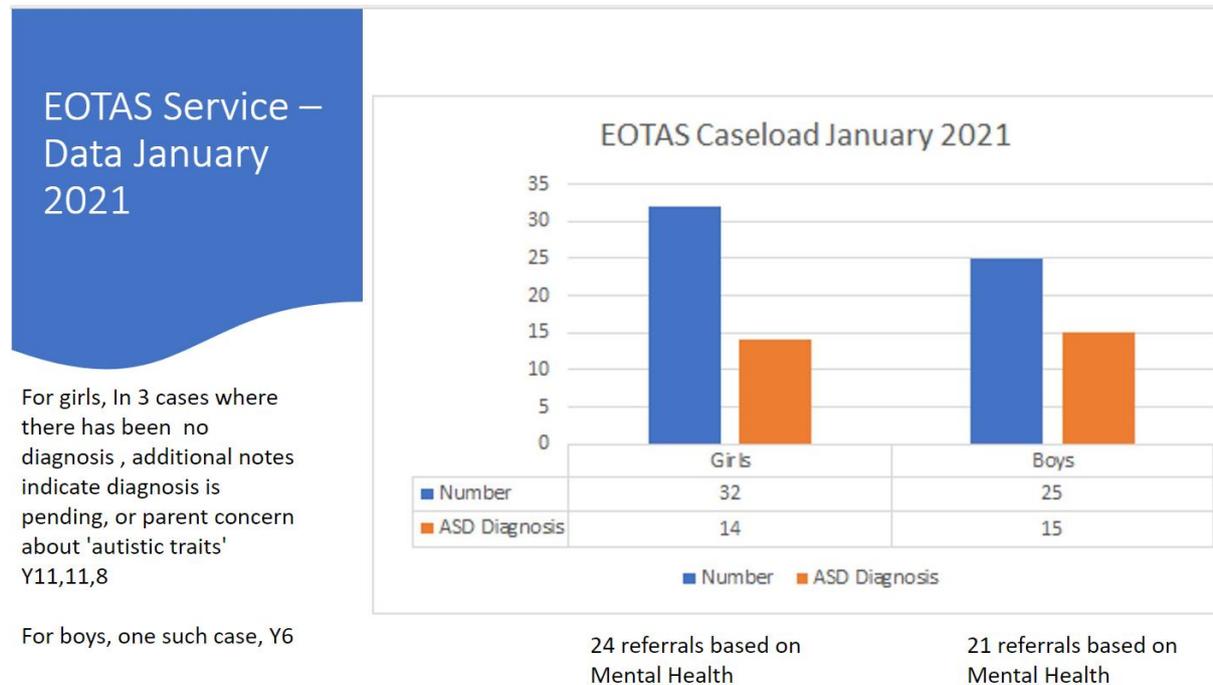
*Data provided* : snapshot of the those receiving support from EOTAS in January 2021

*Data limitations* : trend data is not available

A snapshot of the EOTAS caseload in January 2021 showed

- 51% of all children receiving support from EOTAS had a diagnosis of Autism
- 43% of girls receiving support from EOTAS had a diagnosis of Autism
- 60% of boys receiving support from EOTAS had a diagnosis of Autism

For more detail see below.



The following shows a breakdown of boys and girls with Autism receiving support from Autism according to school year group in January 2021. Girls are more prevalent in the older age groups compared to boys.



## Primary Mental Health Team, Northumbria Healthcare NHS Trust



Primary Mental Health service is an early intervention and prevention service providing support and advice for children and young people up to the age of 18 and their families and carers. They offer support to children and young people experiencing a moderate range of emotional wellbeing and mental health problems such as:

- Anxiety including panic, social anxiety and phobias
- Habitual behaviours of an obsessive compulsive nature
- Low mood and depression
- Managing emotions and anger
- Poor body image
- Self-harm
- Difficulty in adjusting to traumatic life events including parental separation, bereavement and bullying
- Behavioural issues

Young people access the service when the above issues are moderate in nature, the issue has not been resolved following initial help at school or at home, and when it is having a significant impact on their day to day life.

*Data provided* : Primary and secondary referral reason.

*Data limitations* : Data is not able to be split by gender, however average gender split is approximately 50% / 50%. Reasons for referral are recorded as primary and secondary reasons. During the recording period definitions changed from 'Autism' to 'Diagnosed Autism' and 'Suspected Autism'.

From 1.3.20 - 28.2.21

- 10% of all referrals had either a primary or secondary Autism related category
- Of these 108 have a primary reason as Autism and 55 as a secondary reason
- For those categorised in the old category of 'Autism' there were 23 recorded as a primary reason and 11 as a secondary reason
- For those in the new coding for those with 'diagnosed Autism' as a primary source 10 and 9 for secondary
- For those in the new coding for those with 'suspected Autism' as a primary source 53 and secondary source 26.

## Pre-School Autism Diagnostic Pathway, Northumbria Healthcare NHS Trust



Northumbria Healthcare delivers a pre-school autism diagnostic pathway for children aged 0-4 years.

*Data provided* : Numbers of children referred to the pathway per year (January – December) split by gender.

*Data limitations* : This is a simple count of referral numbers and is not representative of activity.

<b>Pre-school ASD Diagnostic Pathway, NHFT</b>				
	<b>2017</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>
<b>Total referred</b>	34	63	79	69
<b>Number of girls referred</b>	8 (23.5%)	10 (15.9%)	17 (21.5%)	13 (19%)
<b>Number of girls receiving diagnosis</b>	5 (62.5%)	7 (70%)	12 (70%)	6/6 (100%) 7 waiting assessment
<b>Referred to CNDS</b>	1 /1	1/2	0	0

Over the last four years, on average 20% of referrals to the 0-4 yrs 10 months diagnostic pathway were girls. The average diagnostic rate is 70-75% for both boys and girls referred to the pathway.

### Early Help, Children’s Social Care, NCC



Early Help is about working with children, young people and their families who would like support. Early Help is there to support families at the right time, by the right person and in the right way. It is a consent-based service which involves the whole family and their Networks to come up with solutions to any difficulties or challenges experienced at the time.

*Data provided* : Snapshot in time of the number of children and young people open to Early Help at SEN Support and EHCP, cross referenced to the primary and secondary need recorded by schools.

*Data limitations* : Within education, primary and secondary need is captured from data recorded by schools against 12 nationally set categories. Training and support has been provided to education settings to support the accurate identification and recording of need. There is greater confidence in this data though it is not yet consistently implemented across all schools. Primary and secondary need is recorded for pupils aged 5-18, therefore this data does not cover the full childhood population.

<b>Early Help - SEN Support</b>	<b>Early Help - EHCP</b>																																																									
In Aug 21 = total number of children and young people receiving SEND Support who are known to Early Help was 230 (250 in Aug 20)	In Aug 21 = total number of children and young people with an EHCP who are known to Early Help was 103 (144 in Aug 20)																																																									
Male / Female	Male / Female																																																									
<table border="1"> <caption>PRIMARY NEED - SEN Support</caption> <thead> <tr> <th>Category</th> <th>Male</th> <th>Female</th> </tr> </thead> <tbody> <tr><td>ASD</td><td>12</td><td>8</td></tr> <tr><td>MLD</td><td>24</td><td>17</td></tr> <tr><td>OTH</td><td>7</td><td>4</td></tr> <tr><td>PD</td><td>4</td><td>0</td></tr> <tr><td>SEMH</td><td>68</td><td>25</td></tr> <tr><td>SLCN</td><td>30</td><td>13</td></tr> <tr><td>SPLD</td><td>9</td><td>7</td></tr> <tr><td>VI</td><td>2</td><td>0</td></tr> </tbody> </table>	Category	Male	Female	ASD	12	8	MLD	24	17	OTH	7	4	PD	4	0	SEMH	68	25	SLCN	30	13	SPLD	9	7	VI	2	0	<table border="1"> <caption>PRIMARY NEED - EHCP</caption> <thead> <tr> <th>Category</th> <th>Male</th> <th>Female</th> </tr> </thead> <tbody> <tr><td>Null</td><td>1</td><td>0</td></tr> <tr><td>ASD</td><td>18</td><td>5</td></tr> <tr><td>MLD</td><td>13</td><td>1</td></tr> <tr><td>PD</td><td>2</td><td>1</td></tr> <tr><td>PMLD</td><td>1</td><td>0</td></tr> <tr><td>SEMH</td><td>31</td><td>10</td></tr> <tr><td>SLCN</td><td>8</td><td>4</td></tr> <tr><td>SLD</td><td>2</td><td>3</td></tr> <tr><td>SPLD</td><td>1</td><td>2</td></tr> </tbody> </table>	Category	Male	Female	Null	1	0	ASD	18	5	MLD	13	1	PD	2	1	PMLD	1	0	SEMH	31	10	SLCN	8	4	SLD	2	3	SPLD	1	2
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<b>National DfE primary / secondary codes</b>	
ASD = Autistic Spectrum Disorder	HI = Hearing Impairment
MLD = Moderate Learning Difficulty	PMLD = Profound & Multiple Learning Difficulty
OTH = Other	SLD = Sever Learning Difficulty
PD = Physical Disability	SLCN = Speech, Language & Communication
SEMH =- Social, emotional and mental health	VI = Visual Impairment
SPLD = Specific Learning Disability	MSI = Multi-sensory impairment

At SEN Support, the most common needs of those open to Early Help are SEMH, SLCN and MLD. For children and young people with EHCPs open to Early Help, the most common needs are ASD, SEMH and SLCN.

ASD, SEMH, SLCN are the top three areas of need that are associated with children and young people known to social work and early help services.

### **Children & Young People’s Service, NHS, CNTW**



The Children and Young People’s Service provides a single service to all children and young people aged 0-18 years living in Northumberland who present with mental health difficulties. This includes children and young people who may have learning difficulties and those living in a range of difficult and challenging circumstances.

*Data provided* : the number of referrals from April 2019 to March 2021 who are coded diagnosed / suspected Autism by gender

*Data limitations* : referrals are coded according to information received from the practitioner who made the referral and are therefore not an accurate picture of clinical presentation. Some children and young people are coded differently within the system and then may go on to receive an Autism diagnosis. This information is therefore not an accurate picture of Autism in referrals to CYPS.

Referral reason	Gender	Referrals received Apr 2019-Mar 2020	Referrals received Apr 2020-Mar 2021	Totals
Diagnosed Autism	Female	6	15	21
	Male	17	36	53
Suspected Autism	Female	9	128	137
	Male	33	197	230

Age of female referrals to CYPS with diagnosed / suspected Autism Apr 19 – Mar 21			
Age at referral	Diagnosed Autism	Suspected Autism	Total
4		4	4
5		5	5
6		8	8
7		13	13
8		17	17
9		16	16
10	2	12	14
11	4	12	16
12	4	10	14
13	1	9	10
14	6	13	19
15	3	9	12
16		6	6
17	1	3	4
<b>Total</b>	<b>21</b>	<b>137</b>	<b>158</b>

While the data has significant limitations as detailed above, it does show a steep increase in referrals between the year 2019-20 and 2020-21 which were coded suspected / diagnosed Autism. It is not possible to draw conclusions from the data re gender, other than to note that there are more male referrals coded in this way than female.

### School Data, Northumberland County Council

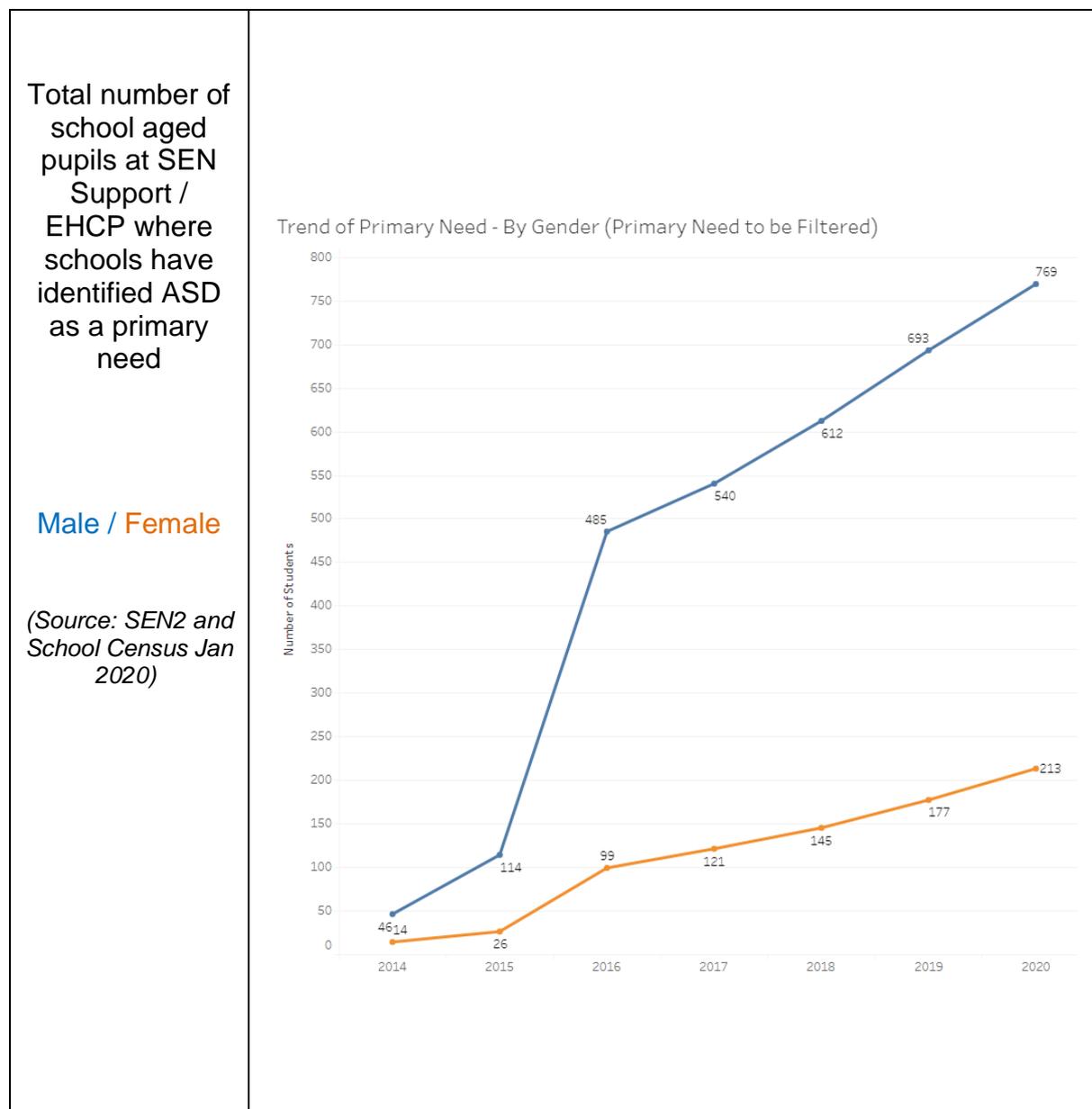


Schools are required to maintain electronic records of pupils who have SEND, whether they are at SEN Support or have an EHCP and code their primary need

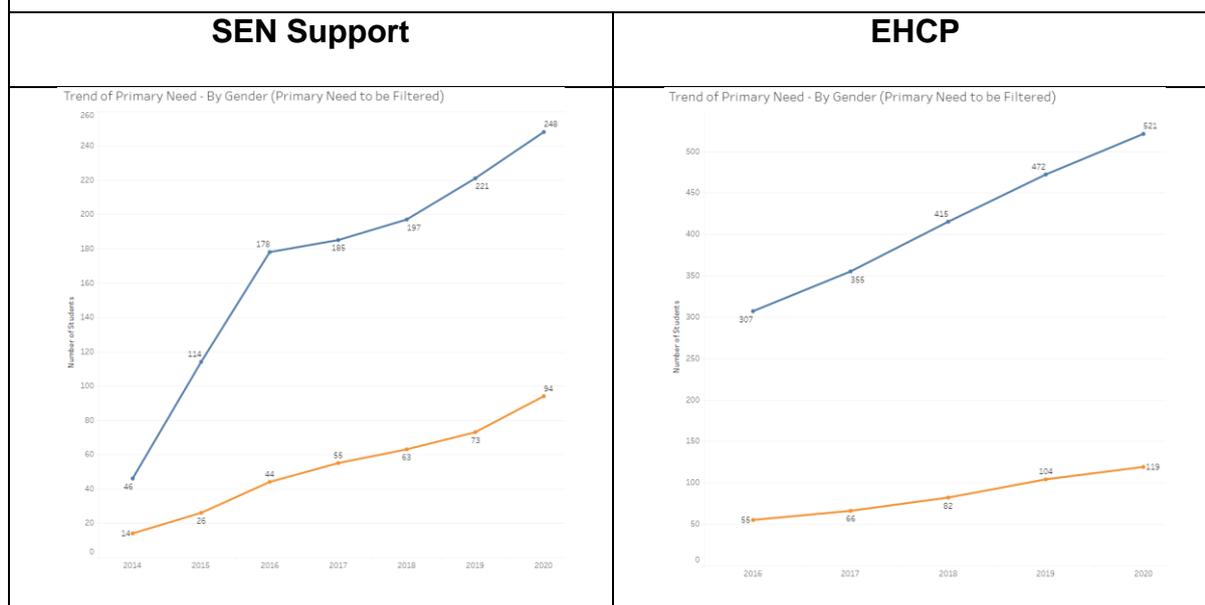
according to 12 categories that are nationally set by the DfE. In Northumberland County Council, this is managed through EMS (Electronic Management System) which can report on the number of children at SEN Support and with an EHCP who have a primary need.

*Data provided* : Snapshot in time (July 21) of the number of children and young people who attend school (ie ages 5-18) at SEN Support and EHCP and their primary need as identified by school / setting.

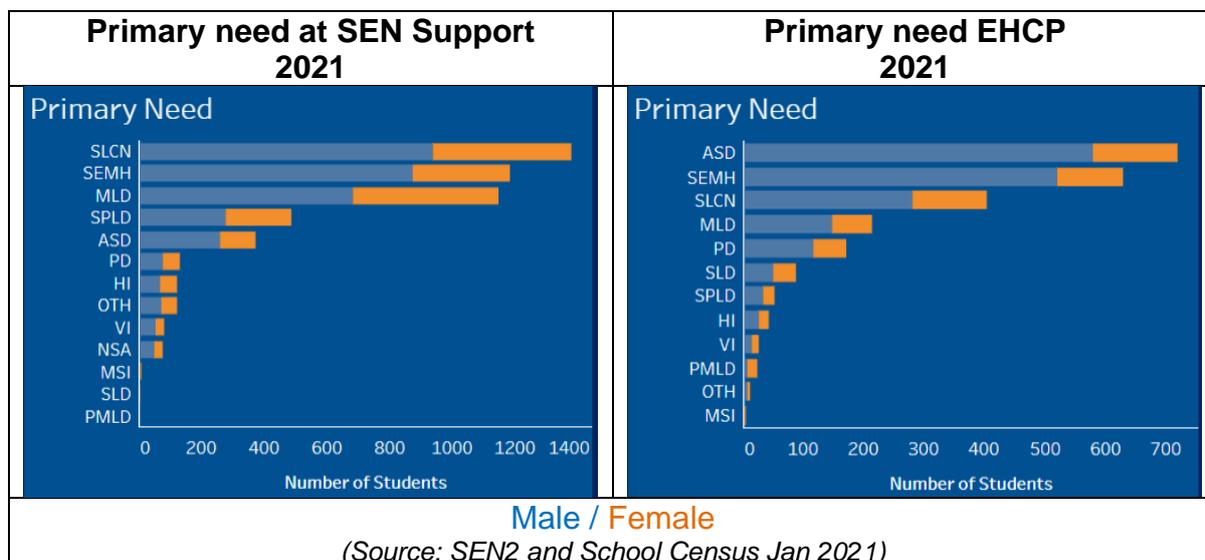
*Data limitations* : Training and support has been provided to education settings to support the accurate identification and recording of need within EMS. There is greater confidence in this data though it is not yet consistently implemented across all schools. Primary and secondary need is recorded for pupils aged 5-18, therefore this data does not cover the full childhood population.



This can further be broken down into



Both SEN Support and EHCP have shown a year on year steady increase in numbers since 2014. SEN Support showed a spike of referrals in 2016, likely to be due to the focus of improvement on understanding and recording of need in 2016.



National DfE primary / secondary codes	
ASD = Autistic Spectrum Disorder	HI = Hearing Impairment
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Across SEND learners, ASD is the highest incidence need for learners with an EHCP and is the 5<sup>th</sup> highest need amongst learners at SEN Support. Compared to SEN Support, more boys than girls who have ASD as a primary need have an EHCP.

## Data Summary

Comments on the data available

- There are a range of different systems that collect data across the Local Area with different systems in education and social care in Northumberland County Council and each NHS provider using a different electronic system.
- These systems do not 'talk' to each other and therefore it was not possible to provide an overall definitive picture of Autism and Girls in Northumberland
- Autism and gender is not consistently collected across all parts of the system and / or existing reporting structures are not able to provide granularity to be able to respond to all of the queries identified by members of the focus group
- Existing systems largely focus on counting activity or measuring length of waiting times for access to services (DATA). These measures are often focussed on organisational performance, rather than on measuring quality of service being delivered (PRACTICE) or the lived experience of children, young people and their families (LISTENING)
- Each data source has its own limitations resulting in it not being possible to draw conclusions about prevalence and possible levels of need

Having detailed all of the above, the following statements can be made

- numbers of children and young people with Autism have been steadily increasing year on year, for both male and female
- more males than females are recorded within data systems as having Autism
- Autism is the highest primary need for learners with an EHCP (30% of plans have Autism as a primary need for male / female)

## Girls and Autism : Research Summary

Alison Walker, Assistant Psychologist produced the following research summary (see appendix 2) detailing what studies have shown in Autism and males / females.

### Assessment and diagnosis

- Assessment of Autism has been criticised for being male biased: that is, the criteria are not universal but are based on behaviours that have been observed in boys, more of whom are therefore diagnosed (Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015).

- Research suggests that Autism becomes more evident (observable) in girls in the secondary phase of schooling (Cook, Ogden & Winstone, 2018), where social demands increasingly require girls to 'fit in' and their relationships rely more heavily on communication and the reciprocal sharing of interests than those of boys. Age and developmental stage may therefore exert an effect.
- There is debate on whether girls have a different phenotype or whether they are simply better at 'camouflaging' or 'masking' their Autism (Bargiela, Steward & Mandy, 2016; Parish-Morris et al., 2017), resulting in underdiagnosis in this population (Begeer et al., 2012)
- In terms of a diagnosis, whether symptoms differ between boys and girls or not, they should:  
 "...cause **clinically significant impairment** in social, occupational, or other important areas of current functioning." (Diagnostic and statistical manual of mental disorders, 2013)

### **Ratio (boys:girls)**

- Numerous studies (Kirkovski, Enticott & Fitzgerald, 2013; Milner, McIntosh, Colvert & Happé, 2019) suggest that the ratio of autistic males to females ranges from 2:1 to 10:1.
- An interaction with performance on 'IQ' assessments has been evidenced, which contributes to this variability: the closer ratio has been observed in cohorts with a lower mean 'IQ', suggesting that girls with a higher 'IQ' are either less likely to have Autism or are more skilled at either coping with or camouflaging it (Dworzynski, Ronald, Bolton & Happé, 2012; Halladay et al., 2015), so it does not have a clinical impact on their functioning as so would not meet diagnostic criteria.
- The most-up-to-date estimate, based on a meta-analysis of prevalence studies, is 3:1 (Loomes, Hull & Mandy, 2017).

### **What the research says: particular to girls with Autism (compared to boys)**

Research suggests the following about girls identified as having Autism:

- Girls have fewer repetitive or restricted behaviours than boys (Frazier, Georgiades, Bishop & Harden, 2014; Van Wijngaarden-Cremers et al., 2013); their repetitive behaviours may be more subtle e.g. nail biting or chewing (Ozsivadjian, Knott & Magiati, 2012).
- Eating disorders experienced by girls (anorexia nervosa) may be interpreted as the manifestation of a restrictive and repetitive behaviour (Odent, 2010).
- Girls have similar interests to typically developing girls, but their focus differs in terms of intensity (Gould & Ashton-Smith, 2011). Boys tend to have different interests to their typically developing peers.
- Girls self-manage / make modifications to cope (Moyse & Porter, 2014) e.g. arriving to class early to avoid sensory overload on corridors.

- Girls are more socially motivated than boys but lack the necessary skills to form / maintain friendships (Attwood, 2007; Lai, Lombardo, Auyeung, Chakrabarti & Baron-Cohen, 2015; Sedgewick, Hill, Yates, Pickering & Pellicano, 2015).
- Girls report fewer socio-communication difficulties than boys, although their perception of their friendships may not be mutual (Dean et al., 2014).
- Girls report less conflict in relationships than typically developing peers, although research suggests that girls with Autism may find it difficult to identify conflict, which contributes to their failure to report it (Sedgewick, Hill, Yates, Pickering & Pellicano, 2015).
- Girls adopt compensatory behaviours e.g. staying close to peers but not engaging with them and / or learning from others (that they should make eye contact, for example), contributing to the superficial appearance of successful social interaction (Dean, Harwood & Kasari, 2016).
- Girls copy / clone / echo the speech of others to the extent that they may even adopt a different persona in their interactions (Attwood, 2007). This is a form of 'masking': they display what appear to be socially appropriate behaviours but lack the understanding and meaning of their interactions (Kopp & Gillberg, 1992). What they say and do may also extend the repertoire of interests that an observer might credit them with, when in fact they are simply repeating those of others. It is difficult to ascertain whether this is done consciously (learned behaviour) or subconsciously (by mimicking others).
- Girls with Autism are 'overlooked' (ignored / not acknowledged as a friend or member of a peer group) by typically developing peers, whereas boys are overtly excluded (Dean et al., 2014). The social isolation of girls may therefore be more difficult to identify; girls with Autism are more likely to be 'overlooked' during adolescence, due to the pressures to conform / fit in with others (Cook, Ogden & Winstone, 2017; Cridland, Jones, Caputi & Magee, 2013; Moyse & Porter, 2014).
- Girls appear more content in their own company (Baldwin & Costley, 2015; Milner, McIntosh, Colvert & Happé, 2019) and find the demands and disappointments of social interaction more of a burden on their psychological wellbeing than boys.
- Girls exhibit less of an autistic behavioural presentation (Hull, Mandy & Petrides, 2016) as they internalise behaviours, including aggression and anxiety (Solomon, Miller, Taylor, Hinshaw & Carter, 2011; Mandy et al., 2011; Jarman & Raynor, 2015; Moyse & Porter, 2014). Boys commonly externalise behaviours – episodes of violence are often the trigger for concern / assessment for Autism (Kopp & Gillberg, 1992).
- Girls experience fatigue as an outcome of the cost of coping / masking of autistic traits (Jarman & Rayner, 2015), leading to exhaustion / meltdown and increased levels of anxiety (Cage & Troxwell-Whitman, 2019).

- Girls are reported to exhibit more behaviour problems at home than they do in school as a result of the above (Cook, Ogden & Winstone, 2017): the effort exerted during the school day affects behaviour beyond it.
- Girls experience an increased amount of anxiety: symptoms seem to be more prevalent in girls with Autism than boys and these symptoms increase during adolescence (May, Cornish & Rinehart, 2013; Solomon, Miller, Taylor, Hinshaw & Carter, 2011).
- Girls are more likely to present as perfectionists: excessively self-critical and afraid of failure (Ashburner, Ziviani & Rodger, 2010; Gould & Ashton Smith, 2011).
- Girls experience impaired executive function: there is some evidence to suggest that girls with Autism experience greater difficulties with planning, goal setting and working memory than boys (Hull, Mandy & Petrides, 2016) and inhibition (Lemon, Gargaro, Enticott & Rinehart, 2010), when compared to boys with Autism and neuro-typical control groups.
- 'Tomboy' appearance / gender identification: qualitative studies suggest that girls with Autism are aware that they are 'different' to their typically developing peers - those who do not identify with habits / choices / pastimes of these peers do not, therefore, identify as female ("I'm no good at being a girl", (Milner, McIntosh, Colvert & Happé, 2019)).
- Epilepsy may be more common in girls with Autism (Danielsson, Gillberg, Billstedt, Gillberg & Olsson, 2005; Turk et al., 2009).

### Caution

It is difficult to ascertain the robustness of studies and the extent to which outcomes can be synthesised, given the differences in research design and sampling rationale (Tomlinson, Bond & Hebron, 2019). In addition, the extent to which girls 'mask' is difficult to assess / measure, as it requires girls to be aware of and able to communicate what it is that they are doing, when their behaviours may not be conscious acts on their part (Hull et al., 2018).

### Research already incorporated into testing

To reflect the above debate / concerns, the Autism Spectrum Screening Questionnaire (ASSQ) has been revised to capture what may be considered as female presentations of Autism spectrum disorders. It now includes ASSQ-GIRL items that differentiate between girls with Autism, their typically developing peers and presentations that are now considered more typical of boys. ASSQ-GIRL items include "avoids demands", "very determined", "careless with physical appearance and dress" and "interacts mostly with younger children" (Kopp & Gillberg, 2011).

In addition, the DMS-5 diagnostic criteria for Autism now reads:

**“Symptoms must be present in the early developmental period** (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).”

(Diagnostic and statistical manual of mental disorders, 2013)

This incorporates both the notion of 'masking' and the fact that differences in the presentation of Autism in girls and boys do not appear to be apparent in "toddlerhood" (Halladay et al., 2015; Reinhardt, Wetherby, Schatschneider, & Lord, 2014; Postorino et al., 2015).

## **Recommendations**

### **Co-production**

1. The lived experience of girls with Autism and their families be more routinely listened to and understood to ensure existing systems can facilitate early diagnosis
2. How and when support for parents and carers in understanding and supporting their daughters needs is considered within the system

### **Data collection**

3. There is system wide consideration of data requirements to underpin strategy and planning for Autism in general, and particularly for girls and Autism around prevalence and need

### **Workforce development**

4. Increase the early identification of Autism in girls through raising awareness of the difference in presentation across teams in education, health and social care

### **Clinical pathways**

5. The difference in clinical presentation be more actively considered in triage and diagnostic pathways across NHS providers
6. Support pathways are reviewed for those who have additional health needs with Autism to ensure that the diagnosis of Autism does not preclude the receipt of support for other conditions

## APPENDIX 1 – List of Contributors

We would like to thank the following contributors for their involvement and support in this work

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## APPENDIX 2 – References from research summary

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