



**SENDIASS/ Health CCG Autism Termly Report  
1<sup>st</sup> August 2021 – 20<sup>th</sup> December 2021**

# Contents

1. Introduction .....	2
2. Advice line / advice sessions - feedback from parents.....	3
3. Referrals .....	3
Age range.....	5
Gender .....	6
Co-morbidity .....	6
Postcode - locality .....	7
Intervention level .....	8
Intervention level by type of support requested.....	8
4. Engaging with parents .....	10
Workshops .....	10
Coffee mornings.....	11
Parents and carers questionnaire.....	12
5. Schools .....	13
6. Appendix.....	15
SENDIASS intervention levels.....	15
Parent and carers responses .....	16

## 1. Introduction

**Measuring performance will consist of both quantitative and qualitative data gathering using evaluation feedback at closure and throughout the process using on-line, social media, paper and face to face questionnaires.**

**The service will continue to report termly to the CCG on the numbers of queries from families where autism is the primary need. This will include year on year trend data, be given as a percentage of overall queries and will detail demographics such as autism status, age, postcode and so on.**

**The service support the signposting of families towards advice and guidance and will use data and conversations with families to highlight any perceived gaps in provision and support.**

## 2. Advice line / advice sessions - feedback from parents

Since the last reporting term, Leeds SENDIASS now deliver advice through both 15-minute triage discussions with an advice line officer (delivering immediate advice and signposting to services and self-service routes), as well as more in depth, 45 advice sessions with an officer. This has enabled the officers to gather information from parents about their needs in more detail.

Through direct and incidental discussions, it continues to be apparent that parents and carers feel there is a lack of information for families with a child/young person with a recent diagnosis of autism. (see responses from parent/carer questionnaire section for more information).

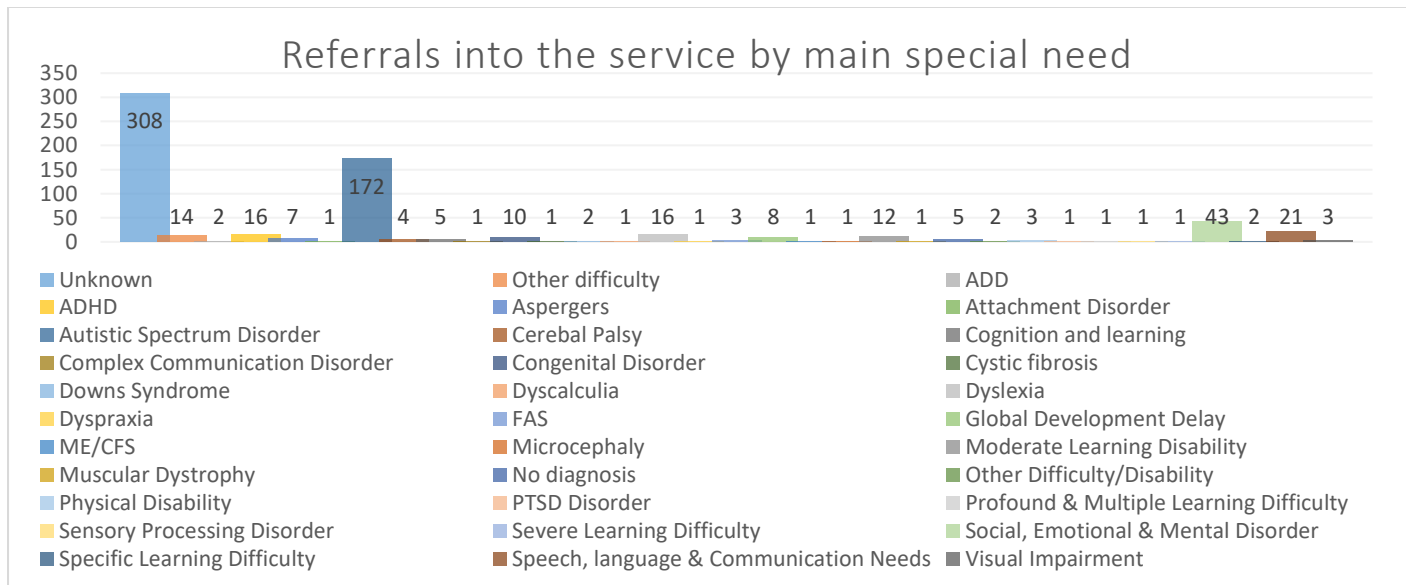
We are still seeing a large number of queries when a new diagnosis of autism is given. Many Leeds families are continuing to receive an outsourced diagnosis and, as we reported in the last term, one of the recommendations in these outsourced reports is to apply for an EHCP. We are now able to provide parents with comprehensive signposting to outside agencies and support groups which has meant we are able to keep some of these queries at L1 support.

L1 and L2 requests for support continue to be largely around EHCPs and L3 requests are around both EHCPs and school support. The fall in level 1 and 2 requests for SEN support could be attributed to the comprehensive workshops, webinars, website and support materials that have been produced since the last reporting term.

## 3. Referrals

There were **670** referrals (either new or existing) in the period 1.8.21 to 20.12.21 (up from **347** last reporting term). Of the total number of referrals in that time **178** (up from **70** last reporting term) were specifically recorded as having either diagnosed or undiagnosed Autism (inclusive of Asperger’s as stated need) as a primary need which equates to **27%** (up from **20%** last reporting term) of all referrals in that time.

The increase in referrals could be attributed to a number of factors: issues within other services in their ability to deliver within specified timeframes and/or respond to enquiries has led to an increase in traffic to our advice line from parents/carers requesting support. We have also significantly increased our social media presence and our private Facebook group now has 347 members. The group, along with our coffee mornings, workshops and parent/carer termly newsletter, have all served to make parents, carers more aware of our service. We have also strengthened our engagement with other professional services, parent and carer groups, charities and support networks.

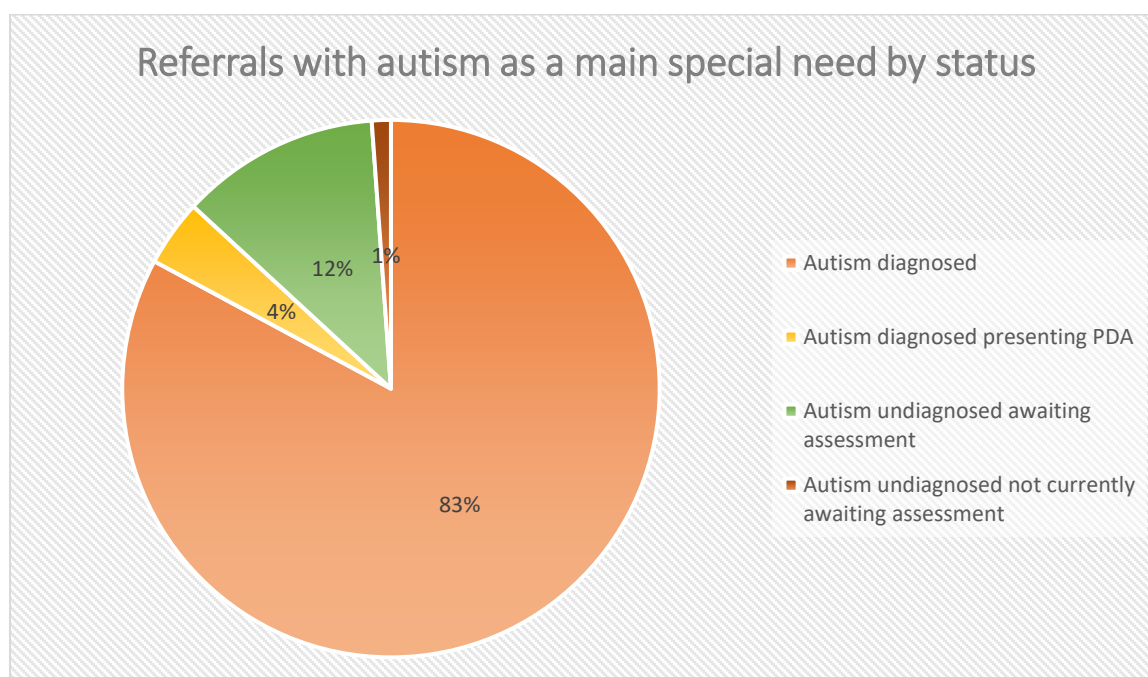


As of July 2021, we are now able to capture ASC data (diagnosed / undiagnosed) on our database for both full referrals and anonymous referrals. Previously the anonymous referrals were all recorded as *unknown special need* due to the nature of the database. The unknown figure relates to the anonymous figures, when Level 1 general advice and/or signposting was given, and a full referral was not taken. Although we are now able to capture much more information around autism status in Level 1 referrals (which is reflected in the information above) in some cases there is insufficient information given in the initial enquiry (such as an email or web contact), there was no opportunity, or it was deemed inappropriate to request the information.

Out of the 178 referrals with Autism identified and the child/young person's main special need, the majority have a formal diagnosis of autism. We are now able to capture information about children and young people who are presenting with autism, without a diagnosis, as well as those with a formal diagnosis of autism. We are also able to record, if the information is available, the number of children with a diagnosis of autism which have a PDA profile (often referred to in a Leeds EHCP as a Demand Avoidance Profile as PDA is not a recognised condition).

#### Break down of autism status within the 178 referrals

Autism status	Number of referrals	Percentage
Diagnosed	145	81%
Diagnosed presenting PDA	7	4%
Undiagnosed, awaiting assessment	21	12%
Undiagnosed, not currently awaiting assessment	5	3%



**The information below further breaks down the 178 referrals in the specified time frame with autism as a main special need, by age range, locality, co-morbidity and level of intervention.**

Where there is no data collected, this relates to a L1 referral for signposting and/or general information which does not require a full referral to be made. The anonymous referrals collect information about postcode and autism status only, when available.

**Age range**

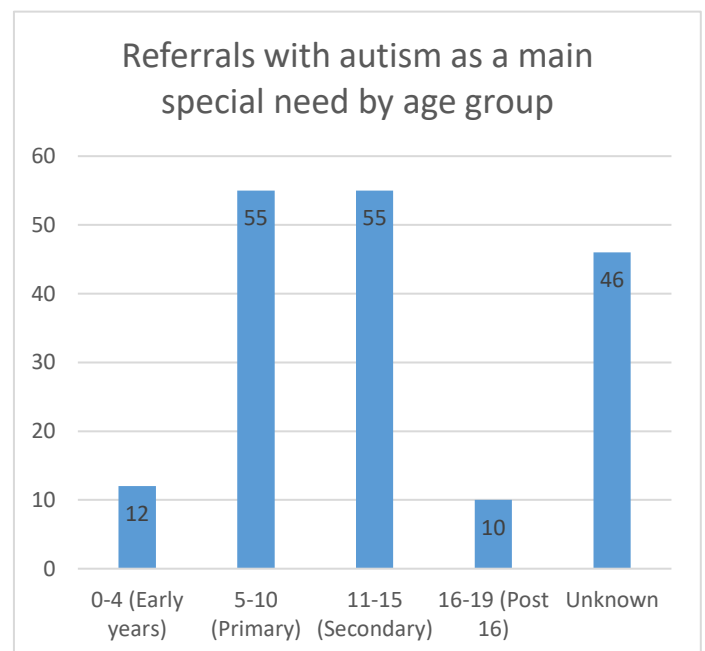
The terms data has shown that the majority of requests for support are still coming from parents and carers of children during their late primary, early secondary school years. It continues to be the case that children with autism generally ‘cope’ with the demands of mainstream education in a primary setting, or at least can mask their issues when in school, although we are seeing an increase in the number of primary aged children not receiving 25 hours (either attending school on a reduced timetable or not attending at all due to anxiety as their needs are not being met).

We previously reported that issues generally begin to develop, and escalate, when the child moves up to high school and they have to deal with multiple changes of routine, a much larger setting, with increased number of students, increased levels of noise and visual stimulus – which can lead to sensory overload, and this still seems to be the same. High schools are not set up to support children with sensory needs and the number of staff available to support these children seems to be significantly smaller than in primary schools. High schools are reporting that they do not have the budgets to fund individual support.

A large number of referrals also come from parents/carers of late primary school age children, when parents and schools apply for an EHC Needs Assessment, in the hope of getting a specialist setting for high school, or when they application has been rejected by the LA as the child is sufficiently supported in the primary setting and they feel there is not enough information about the need for support moving forwards. This also means that parents/carers of children in mainstream secondary schools are looking to us for support as the child has entered high school without the protection of an EHCP, and they are in danger of becoming NEET.

Percentage of referrals in the date range **1.8.21 – 20.12.21** that have BOTH Autism and are in the age range indicated.

Age range	Number of referrals	Percentage of referrals
Not recorded (L1)	46	59%
0 – 4	12	7%
5 - 11 (primary)	55	31%
11 – 15 (high school)	55	31%
16 -19	10	7%



## Gender

In the last reporting term, we found that nearly three quarters of the referrals with autism as a main special need, were from parents and carers of boys. The referrals (level 2 and above) continue to be twice as prevalent in boys. The shift *could* be to do with the different way of recording within our database, but we are also noticing that we are receiving more referrals from parents of girls who are displaying autistic tendencies. There is more information and advice around this subject available to parents and carers, than there ever was before, and we have found that as parents become more informed around autism in girls, we are getting more requests for support – especially around masking in schools.

Percentage of referrals in the date range **1.8.21 – 20.12.21** that have BOTH Autism and are in the gender field indicated.

Gender	Number of referrals	Percentage of referrals
Not recorded (L1)	41	23%
Male	99	56%
Female	38	21%

## Co-morbidity

The data base was amended in July to accurately reflect referrals, with a main need of autism, that also had additional needs in other areas.

The data previously showed most common comorbidity noted were generally from the Specific Learning Difficulties (SpLDs) umbrella - dyslexia, dyscalculia, dysgraphia - however, this terms data shows ADHD is now the leading additional need, with the number of referrals stating Social, Emotional and Mental Health (SEMH) issues as a secondary need, has risen.

As noted previously, children and young people with autism, who are academic and in a mainstream setting, suffer from extreme anxiety and that this is exacerbated by their mainstream environments. There many children with both autism and SEMH presentations do not meet the criteria for many autism specific specialist settings, and the SEMH settings often have children with high tariff behaviours and cannot provide the low arousal surroundings that are needed.

Percentage of referrals in that date range **1.8.21 – 20.12.21** that have BOTH Autism and have a secondary diagnosis/need as indicated.

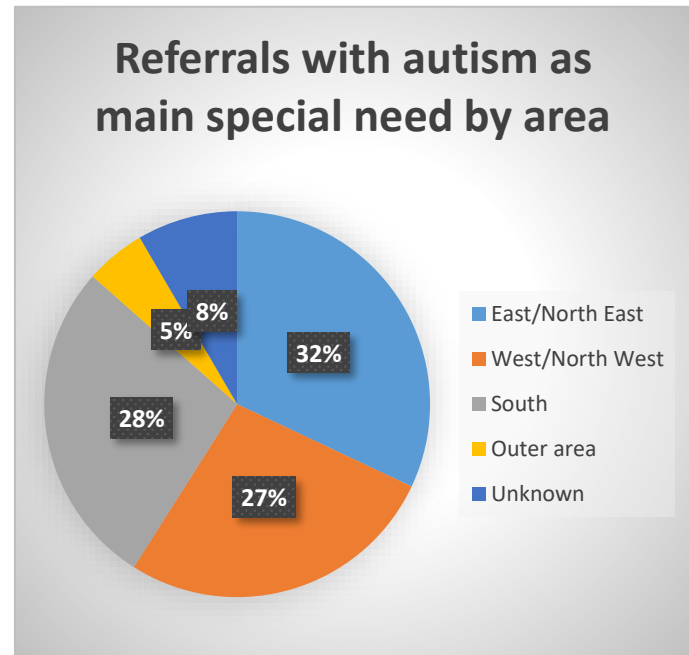
Co-morbidity	Number of referrals	Percentage of referrals
SEMH	19	11%
Global Development Delay	2	1%
ADHD	30	17%
Dyslexia	8	4%
DCD	2	1%
Neurological	2	1%
Moderate Learning Difficulty	2	1%
Severe Learning Difficulty	1	1%
Hypermobility	2	1%
Speech, language and communication difficulties	8	4%
ODD	1	1%

## Postcode - locality

In this reporting term, we have found requests for support from parents/carers of children and young people with autism have been more equally spread across the city. There has been an uptake in requests from schools in the east and south of the city for us to host drop-ins in schools, as they are finding that parents are needing support as their children leave primary school, especially around finding appropriate settings and EHCP Needs Assessment requests.

Percentage of referrals in that date range 1.4.21 – 31.7.21 that have BOTH Autism and are in the postcode as indicated.

Postcodes	Number of referrals	Percentage of referrals
Not recorded	15	8%
LS5	2	1%
LS6	5	3%
LS7	4	2%
LS8	17	10%
LS9	12	7%
LS10	7	4%
LS11	5	3%
LS12	7	4%
LS13	10	6%
LS14	10	6%
LS15	10	6%
LS16	4	2%
LS17	13	7%
LS18	7	4%
LS19	1	1%
LS20	3	2%
LS22	1	1%
LS23	3	2%
LS25	4	2%
LS26	8	4%
LS27	8	4%
BD3	2	1%
WF3	7	4%
WF10	1	1%



## Intervention level

Leeds SENDIASS categorise the information, advice and support that is given to parents, carers or children and young people into four categories of intervention level. These levels have been determined by the Information, Advice and Support Services Network, and is adhered to nationally by all IAS services (see appendix for further explanation).

Of the **178** referrals made (with autism as the main special need) in the identified time period, most of the requests for support were at Level 1 or Level 3.

The rise of Level 1 referrals can be attributed firstly to the enhanced system of recording anonymous referrals, with the emphasis on collecting information about autism status when appropriate, so we have been able to capture anonymous referrals in more detail (previously, these were not always entered into the system). Secondly, we have developed a comprehensive set of resources (including guides, FAQs, factsheets, webinars and the website) which we are able to send out to parents in the first instance. The website also allows parents to self-serve to a better degree (which can also be achieved through L1 signposting) so they can be comprehensively equipped in a relatively short time, whereas in previous years the information would have been delivered through meetings and advice sessions, which would require a full referral (at level 2 or 3) to be taken.

Percentage of referrals in that date range **1.8.21 – 20.12.21** that have BOTH Autism and intervention level as indicated.

Intervention level	Number of referrals	Percentage of referrals
L1	62	34%
L2	45	25%
L3	56	31%
L4	15	8%

## Intervention level by type of support requested

This can be further broken down into the type of support requested - much of the information, advice and support that is sought by our service users is around school support and EHCPs. There continues to be a cross over in these areas and many parents and carers contact us to ask about the route for applying for an EHC Needs Assessment as their child/young person's current mainstream setting is not meeting needs, they feel the school is failing their child or their current environment is not right for their child's needs.

We have also seen an increase in the number of referrals, where the child/YP has autism as a main need, in level 4 SEND Tribunal cases. The majority of these referrals, including requests to attend mediations with the local authority, has been around the decision to not go ahead with a EHC needs assessment. Leeds SENSAP report that they have an unprecedented number of applications at the moment, and children with autism, who are receiving a high level of support in their primary setting, are receiving a 'no to assess' – despite the views of the parents, carers and school that the child will not cope with a mainstream high school. In some cases, the recommendation for an EHCP came as part of the autism assessment report, but the school and the LA do not feel this is needed and that their needs can be met in a mainstream, setting, with a robust graduated response.

Percentage of referrals in that date range 1.4.21 – 31.7.21 that have BOTH Autism intervention level defined by type of support as indicated.



Intervention level	Number of referrals	Percentage of referrals
L1 – Signposting	15	8%
L1 – ECHP	21	12%
L1 – SEN support	14	8%
L1 – Admissions	3	2%
L1 – Tribunal	1	1%
L1 – Complaints	1	1%
L1 – Not receiving 25 hrs	5	3%
L1 – Exclusions	1	1%
L2 – EHCP	29	16%
L2 - SEN support	10	6%
L2 – Transport	1	1%
L2 – Exclusions	2	1%
L2 – Complaints	1	1%
L2 – Not receiving 25 hours	2	1%
L3 – School SEN support	27	15%
L3 – EHCP	29	16%
L4 – Tribunal	15	8%

### Overall findings – parents and carers with children/YP with autism as a main special need

The information this term continues to show that the majority of referrals into our service, when a child has autism as a main special need, are for white British boys in secondary schools, and this group also have significant SEMH issues. Anecdotally, we also know that there is a rise in the number of referrals coming in from parents of girls, especially those that mask. Specifically, there is an uptake in requests for support where parents have been through the Mindmate referral process, schools have reported that there are no issues in school (due to masking) and therefore the request for assessment has not been taken any further forward.

In terms of referral levels, the increase in referrals linked to tribunals (2.6% up to 8%) has mainly been around support at mediations and appeals against the local authority decision not to proceed with an EHC Needs Assessment.

## 4. Engaging with parents

### Workshops

Our workshops continue to be well received and cover a range of topics, with two new workshops introduced September. 79% of parents and carers that have attended our workshops already have a child either diagnosed or awaiting diagnosis of autism, so this is taken into consideration when planning and delivering these sessions.

#### Workshop data August – December 2021

<b>EHC Needs assessment (4 workshops)</b>	
<b>Number of attendees booked on</b>	<b>Child/YP with diagnosed/suspected Autism</b>
49	38
Percentage ASC - 78%	

<b>SEND Support in schools (3 workshops)</b>	
<b>Number of attendees booked on</b>	<b>Child/YP with diagnosed/suspected Autism</b>
26	21
Percentage ASC - 81%	

<b>EHCP Review (2 workshops)</b>	
<b>Number of attendees booked on</b>	<b>Child/YP with diagnosed/suspected Autism</b>
9	8
Percentage ASC - 89%	

<b>Appealing to the SEND Tribunal (2 workshops)</b>	
<b>Number of attendees booked on</b>	<b>Child/YP with diagnosed/suspected Autism</b>
14	10
Percentage ASC - 71%	

<b>Next Steps after DAP (2 workshops)</b>	
<b>Number of attendees booked on</b>	<b>Child/YP with diagnosed/suspected Autism</b>
3	3
Percentage ASC - 100%	

<b>Preparing for Adulthood (2 workshops)</b>	
<b>Number of attendees booked on</b>	<b>Child/YP with diagnosed/suspected Autism</b>
9	7
Percentage ASC - 78%	

<b>Total number of attendees</b>	<b>Total number of Child/YP with diagnosed/suspected Autism</b>	<b>Percentage of attendees children with ASC</b>
110	87	79%

SEND support in schools and applying for an EHC Needs Assessment continue to be our most popular workshops, with a large percentage of the parents and carers attending having children with diagnosed or undiagnosed autism.

A new workshop was introduced from September around appeals due to number of children/young people with ASC receiving a *No to Assess* to an EHC Needs Assessment (from September 2021) or appealing Part I as no appropriate specialist setting is available. Although these workshops are not specifically related to autism, 79% of parents and carers that have attended our workshops already have a child either diagnosed or awaiting diagnosis of autism, so this has been taken into consideration when planning and delivering these sessions.

## Coffee mornings

Through delivering workshops, we realised that there was a need for a more informal forum for parents and carers to get together to discuss issues and express their views. Since October, three coffee mornings have taken place for members of our closed Facebook group, hosted over Zoom. We sent out a poll to parents, via our Facebook group, to find out what topics they would like to discuss, and they requested sessions around EHCPs, SEND support in school and autism support, including PDA profiles.

SENDIASS remained an impartial party in these sessions - the feedback around support for (diagnosed and undiagnosed) autism in children and YP below, was gathered and shared with the permission of the attending parents and carers, from the first two sessions, as they were geared towards parents/carers of children/YP with autism. The views are entirely those of the session's participants.

### Coffee morning #1 – attended by SS from Zig Zag Autism parent support group.

- STARS – the waiting list for support in schools is now very long, parents reporting 1-2 years wait for them to give direct support to pupils diagnosed with autism.
- School refusal – this is a big issue with children with autism. Anxiety around attending is a massive barrier, especially in secondary settings. Mainstream schools are doing their best to support if the child can actually get into school (for example offering reduced timetables) however, there is no support for parents to get the children through the school door, and the parents said they are really struggling with this lack of support. This is then impacting on home life and affecting the mental health of parents and carers.
- Children/YP with SEMH/anxiety who cannot attend mainstream settings, are also struggling to access Medical Needs Teaching Service (MNTS), as there needs to be active CAMHS involvement. Many children/YP are discharged from the service once a diagnosis is given, and it is difficult to get them back on board as their waiting lists are so long.
- Parents reported that CAMHS are not getting back to parents (despite multiple calls and emails) and there are difficulties in contacting practitioners (possibly due to staffing levels). One parent at the coffee morning mentioned that, as a stepping stone between Cluster Services and CAMHS involvement, their NEET child was being offered up to eight sessions of evidence based Low Intensity Cognitive Behavioural Therapy from The Children's Psychological Wellbeing Service. Another offer was that of ACBI (Assessment, Consultation, Brief Intervention), which consists of three sessions. Parents felt that these interventions were difficult to navigate as they are both very prescriptive (described as almost like working through a ladder, regardless of whether the rungs were appropriate). The prescriptive nature has meant that the children are finding it difficult to engage with these interventions (as they are primarily mental health interventions which are not autism friendly), which means they are not helping to get the children back into school.

- Cluster and school support – parents view is that the Cluster do their best to help, within their very limited capacity, but they do not often have the correct training to deliver counselling to children and YP with autism. The waiting list for Cluster support is very long (parents citing a year long wait) and many of the workers are not autism specialists, so they do not have the training and/or understanding to deal with children with autism. The Cluster support is generally time limited, and they are often not able to extend their support beyond these timescales, even when there is a very real and clear need for extensive input. There is also an issue with many academy schools withdrawing from Cluster support, but lacking a robust, autism friendly offer in its place.

### Coffee morning #2 – attended by LJ from The Lightbulb Moment (PDA support parent support)

- Main concern from parents is that Leeds Community Healthcare NHS Trust does not consider PDA as a distinct diagnostic label. Some parents have paid privately for a PDA diagnosis, but these have not been recognised/accepted by the school. This means that many mainstream schools do not have the strategies in place to deal with children/YP with a Demand Avoidance Profile and/or are not able to access support for their pupils. Parents also report that they feel they are blamed for their child/YPs behaviours, as if they are a behaviour choice that is exacerbated by bad parenting.
- It's often the case that PDA is not written into an EHCP (although we are seeing some references to Demand Avoidance Profiles), which means there is an unmet need with no tangible outcome in many plans.
- There are no specialist schools or settings in Leeds that state that they can meet the needs of children/YP with a PDA profile. The settings (such as Witherslack schools) who can, are out of authority and come with a cost to Leeds LA. If the schools were to be agreed to by the LA, there is often a lengthy commute involved that many children with autism cannot deal with – so these OOA schools are ruled out for them.
- Mainstream schools feel pressured to meet need as there is a lack of specialist settings, but they are unable to access the support they need, in order to support the pupils fully. Children and YP are then not able to access school, and more and more children are either remaining NEET or are looking to go down the EOTAS route.

### **Next Steps**

To attend ZIG ZAG parents' group in the first instance to gather information on need and gaps in provision for parents/carers of children and young people with autism. This action was put on hold as the service has not resumed their face-to-face sessions due to the ongoing pandemic.

To discuss further topics such as placements and settings, tribunal, and parental support networks with parents and carers through a variety of different forums

### **Parents and carers questionnaire**

The questionnaire was originally shared through our Facebook page. Initially, there was a great deal of interest in filling out the questionnaire – with group members being very vocal that there are many gaps in services and support for families of children/YP with autism. However, there was a limited number of replies once they had been sent out. At the SENDIASS steering group recently, the feedback was that the word document felt too cumbersome and time consuming for some parents to use. Working with LLO, the questionnaire has now been changed into a more accessible weblink – this will be reshared with our group members, and other parent support groups, as well as on the LLO webpage. Some of the parents views and responses already collated, can be found in the appendix below.

## Summary of findings

The majority of diagnoses were through outsourced agencies after a significant time on the CAMHS waiting list. Parents report that the advice and information given from the different practitioners (Healios, Clinical Partners etc) is inconsistent and ranges from nothing to a generic list of support services – but parents felt generally unsupported after the diagnosis was received. Another issue is that once a child receives a diagnosis, they are discharged from CAHMS with no follow up information and getting back on the waiting list (for additional support or medication) is a lengthy process.

The information given to parents after the initial diagnosis is brief and seems to point mainly to STARS and their Cygnet course, however the waiting lists themselves for the courses are extremely long - in some cases parents have been advised up to 2 years.

There are further inconsistencies around schools and recommendations for support – many of the referral requests we receive as a service are for school support, as parents do not know how to approach schools, and what they can and/or should be asking for. This is also the picture for clinicians recommending an EHCP, without discussions with the school around whether they feel the child's/YPs needs could be met in their setting through a robust graduated response and/or whether a move to specialist was needed.

In terms of parent support, there is no formal support package for parents and many parents feel that the onus is on themselves to find the support they need. The most common support parents have cited is through parent carer groups such as ABC and Zig Zag, which have been set up by parents themselves when they couldn't find support. These groups give tremendous support, but they lack the funding and reach to support all the parents who would benefit. Again, this proves an issue for these parents who do not have access to the internet (which seems to be the main way parents find support) or to other ways to find support groups in their areas.

Aside from parent support groups, there is a clear lack of professional support, especially when there is comorbidity, and most parents simply do not have the money to pay for private support. Schools differ vastly in what they can offer in terms of support and it is very much a lottery as to which school the child attends and therefore the support they receive. In other cases, schools try their best to support the children/YP, but they are limited in their capacity due to lack of training, lack of funding or staff turnover.

The responses in the appendix give a clear picture of need – parents feel very alone throughout the journey of assessment and beyond.

## 5. Schools

### Feedback from parents gathered in advice calls, advice sessions, workshops, coffee mornings and drop-ins.

There continues to be a significant number of parents contacting our service requesting information about autism specific provisions in Leeds. In response to this, we have put together a guide to autism specific provisions in Leeds and Out of Authority to give parents a wider understanding of what is on offer.

We have also received an update from SENSAP around the new settings and resourced provisions that were/are scheduled for opening in 2021/2022. However, even with the opening of additional Resourced Provisions in September 2021, there are currently not enough specialist places in Leeds (the autism RP at Trinity Academy has been delayed until Sept 2022, the RP at St Margaret's is delayed until later in the year will only have a small initial cohort, and the Dovecote

RP is only accepting Yr. 7 children at present). This has meant that children are remaining in mainstream settings which are not appropriate. As a result, we have seen a big uptake in referrals for children/YP that are non-attending due to anxiety, which is a major concern. We have also seen an increase of parents wanting to apply for EOATAS as there is no package available in either mainstream or specialist settings that can support their child/YP. Parents are also reporting that due to illness and capacity within the SENSAP team, they are struggling to get responses from their SENSAP case officers, which causes a significant impact on consultations.

Mainstream settings are struggling to meet the needs of children and YP with autism and/or autistic traits. Schools in turn are not able to access the appropriate training that they need as the waiting list for STARS training is too long. There is no PDA specific training available, so schools do not know how to deal with children with these profiles or offer PDA specific support. Parents are also reporting a lack of access to professionals (such as EPs, SaLT etc) in school and are having to pay to go privately, which causes further divides for those that are not in the position to do this. Parents are also reporting that there are many SENCOS in schools absent on long term sick leave and this is causing further issues.

Parents are also reporting gaps in provision for co-morbidity – especially those with SEMH in addition to autism. The autism specific settings cannot meet the needs of children/YP who also have SEMH presentations. Many of these children are then directed to SEMH provisions such as Springwell and then the placement fails. These children are in the wrong setting, as they have anxiety due to unmet needs within their autism (such as sensory needs) causing SEMH presentations, not SEMH as a primary need.

The only setting in Leeds that parents feel (on paper) can cater for children with both autism and SEMH presentations is Pivot – but parents are reporting that this is not suitable for many children with sensory or anxiety issues as there is inadequate outside space and there is a risk for absconders due to the setting leading out onto a carpark (among other reasons).

Another issue highlighted is that there are no settings with a comparable therapeutic offer in the Leeds area similar to those Out of Authority (OOA). The Armley Grange provision Which opened in September 2020 offered child centred education to nurture social and emotional development, prepare students with a range of presentations, including autism, for their adult lives and promote independence. However, this setting closed 10 month later and when parents contacted them, they were told there was no call for an SEN school in the area. Another issue highlighted was the lack of residential settings in the Leeds area.

## **Next Steps**

To collate data around the number of children with autism (diagnosed or undiagnosed) who are currently missing out on education (not receiving 25 hours) and why they are not attending, the number on part-time timetables or reduced timetable and information on the types of setting (including comments on the perception of their environment) they are attending (this data will be collected from the database and from parent groups).

To run a poll in our Facebook group to gather parental views on settings and need.

To collect data around children and young people (both using our service or through other avenues) that are currently classed as EHE and EOTAS, including how long they have been EHE and if there is a view that they will return to an educational provision.

## 6. Appendix

### SENDIASS intervention levels

The intervention level is identified when a parent, young person or child seeks information, advice or support from the IASS. The intervention level may be revised and moved to a higher level if that proves to be appropriate. If the intervention is deemed active or inactive the casework remains at the highest level of intervention that has been necessary during the current intervention period. If an intervention has been closed and the service user makes a further request for support a new intervention is opened and a fresh decision about the appropriate level should be made.

**Level 1** – Includes information and advice about SEND matters, such as: • the legal framework • local SEN processes and procedures • support groups • particular special educational needs or disabilities • funding arrangements • local services • web-based resources • national organisations

**Level 2** – Includes any or all of Level 1 plus: • help to understand or complete documentation • support in communicating with school, the LA, other services, etc. • detailed and personalised guidance on following SEND or exclusion procedures • assistance in accessing services

**Level 3** - includes any or all of Levels 1 and 2 plus: • detailed and continuing assistance and guidance with statutory processes • complex, multi-agency needs • assistance in overcoming serious breakdown in communications with school/LA/other services • requires intensive support due to personal circumstances (e.g. low literacy levels, learning or sensory difficulties, English as a second language)

**Level 4** – includes any or all of Levels 1,2 and 3 plus: Detailed and continuing assistance and guidance with preparation and support during: • First Tier Tribunal (SEND), including DDA complaints to Tribunal • Complaints to Ombudsman • Judicial Review • Disputes about Child Protection



Leeds SENDIASS

Special Educational Needs and Disabilities Information Advice Support Service

## Autism support questionnaire.

The following questions were shared with members of the Leeds SENDIASS Facebook group. This was also shared with Carers Leeds and Zig Zag Autism support network. Below is some of the information collected from parents and carers of children who have been through the diagnosis process.

All comments from parents and carers have been recorded verbatim.

**Did your child/young person receive a diagnosis through the NHS, or did you pay for a private diagnosis? Which service did you receive a diagnosis through?**

- It was through Clinical Partners but through the NHS
- NHS – (CAHMS)
- We had an NHS diagnosis outsourced to Socrates, Huddersfield CAMHS after going to paediatrics for 2 years before they referred her
- My son was diagnosed with autism by Healios, on behalf of CAMHS. I paid for a private diagnosis of Sensory Processing Issues.
- Two children, both through NHS / CAMHS but the process and diagnosis was through Clinical Partners
- NHS referral from CAMHS Clinical partners.
- NHS CAHMS outsourced to Clinical Partners
- NHS Diagnosis CAMHS referred to Clinical Partners to cut waiting lists.

**Were you sent any information around support groups or services when you were given a diagnosis? If so, which services?**

- Yes - Cygnet
- Stars, Cygnet, there were some others, but I can't recall them.
- No. I rang CAMHS after diagnosis and was given information about ABC group ABC parents' group
- Yes, we were given a generic list of support services
- Hardly anything. A brief conversation, and half a page of potential contacts. All of which were from the clinical deficit approach of autism, rather than from the autistic community or pointing in the direction of the neurodiversity movement, positive neurodivergence, etc.
- No
- Briefly mentioned in the report, STARS (but not how to contact them etc), how to access OT and Autism website.
- No apart from Cygnets, which we signed up for, were put on the waiting list and never heard back from. Cygnets, we were added to the waiting list and have not been contacted since.

**Were you given a timeline for accessing support such as the Cygnet group or other services?**



- I was told it would be a short waiting list, but I was waiting nearly 2 years before I was invited to attend
- No, not from CAHMS, although my daughters' school have advised there is a long wait.
- When I went to one of the drop-in sessions at the library I spoke to stars and applied for the Cygnet course myself. We did it about 6 months later.
- I was advised that there would be no follow-on support provided from CAMHS. I can't recall timelines for other support services.
- Yes – but for both children by the time the referral came through they'd move to secondary, and the referral was for primary and removed. To be honest, by then I'd researched so much and had so much experience I could have led the course. We were basically left to sort it out ourselves once we had diagnosis – which was exactly the same as getting to the point of diagnosis anyway.
- No
- No this wasn't mentioned.
- No, we were told the waiting list for Cygnets was approximately 18 months.

**Were you given any recommendations in the report around schools? Were you advised to contact school and discuss the report with the school SENCo?**

- No
- Yes, some advice for school around how they can best support XXXX with her learning, they asked if I would like to share the report with the SENCO – but they didn't send them a copy, I did.
- No not from CAMHS
- There is some guidance on how to best support an autistic child in school, including the transition to secondary school (a book recommendation was made). I advised the clinician that school were heavily involved in supporting my son and were involved in making the referral to CAMHS, so I would be following up with them.
- No. We were told specifically not to share the report with school as it was clinical data related to our child. For our first child, CAMHS expressly ignored this and shred it with school against GDPR. They changed their processes as a result of our complaint.
- No
- Only SEND code of practice and responsibility of schools.
- No, I contacted the school SENCo.
- 

**Were you advised to apply for an EHCP?**

- Yes however 4 years later I still haven't got one due to school
- No, although this is something I intend to raise with the School, having raised it many times at her Primary School and being advised it was unnecessary.
- At the feedback session they suggested an EHCP, but school weren't wanting us to do one at that point. I applied in May of year 6 with the support of STARS. I had help from SCOPE to fill in our sections of the application.
- No, I found this out myself and did my own application
- Yes
- No
- No
- Yes, I asked school for 5 years to assist and when they did, we were refused as the school didn't give enough information even though my child was recognised as having SEN.
- 

**What support services do you currently access? (this could be either professionals and/or parent support)?**

- None

- We have an adoption support worker, on-line (face book group). Our daughter is also to have some work undertaken with regards to sensory skills via One Adoption.
- ABC group and Blossom Tree group on Facebook. ABC meetings f2f when I can attend. Also have done the sleep training through SCOPE during lockdown. My daughter is under CAHMS medication clinic and is awaiting some CBT session with them.
- SENDIASS, various online forums, NHS dietitian and OT, I have just self-referred back to CAMHS due to my son's anxiety and inability to access school. My son was attending Geeks Room autistic mentoring scheme but cannot attend now due to anxiety. My son had 6 sessions of counselling with Pudsey Cluster but there was very limited merit to these as he did not have the opportunity to build any sort of trust with the counsellor.
- Not a lot. There's really no help. You have to do it all yourself. I'd say the most help I get I from other parents who have a similar approach to neurodivergence and online support.
- None
- Only online OD Leeds Zig Zag. Have had one session with STARS and attended one SENDIASS workshop for EHCP.
- None, there is no help readily available after diagnosis.

#### **Have you had to pay for support and/or services?**

- N/A
- No
- No but we are considering a private OT that I have been recommended from another parent.
- Yes, I pay for Geeks Room and I paid for a private OT assessment of Sensory Processing Issues/suggestions for reasonable adjustments at secondary school. I have also paid for autism webinars and specific topic sessions i.e., anxiety in autistic children, autistic burnout. I read books for parents of autistic children and have watched films such as 'The Reason I Jump' to try and build a rounded view of autism and how I can best support my son.
- No
- No
- No
- No were not in a position to do that unfortunately
- 

#### **Where do you find information and support?**

- Our Support worker and the on-line support group currently.
- Online mostly and from a SEND teacher who is my daughter's friend's mum.
- I find support online via webinars and chat groups, discussions with peers who have autistic children, I spend time researching techniques to help i.e., sensory overload, burnout, anxiety. I have had no formal support as the parent of an autistic child apart from the information I have found out for myself.
- Online – academic research – other parents – other Autistic adults
- Peers and social media /google searches
- Online
- Social media and google or we just try to do the best we can.

#### **What areas do you feel are missing in terms of support for newly diagnosed children/YP?**

- I have found I have had to do my own research in terms of support. This is mainly via Facebook
- Information about Autism, reading recommendations and the fact that the wait for support through Cygnet is so long, you wonder if it's worth bothering. Luckily Chloe's school have

a good relationship with Stars and have someone coming into school regularly and she also see the school Autism Lead each week.

- A follow-up session with the young person a few months down the line would be good to see how their diagnosis is helping them. No-one discussed her diagnosis with her except us.
- There is no formal support package for parents and the onus is on each parent to find out as little or as much as they want. There should be support in place for children who have anxiety as a comorbidity of autism and there should be more funding for CAMHS in the wider sense, as waiting lists of over 2 years for CBT etc are unacceptable. There is information available but in order to find this out, you really need to do a great deal of work as a parent. You are also required to become your child's advocate as well as their carer and there is so much to take in when you first get the diagnosis for your child, that you simply cannot be expected to absorb everything you need to do at this point. The best resources I have found are those shared by parents of autistic children who are 3/4/5 years down the line from diagnosis and have been where you are. There is also a good deal of useful content shared by Sensory, OT, autistic advocates that could be incorporated into an online resource.
- Everything – the whole neurodiversity movement should be made aware to parents. Adult Autistic voice should be centred and just isn't anywhere in either support or provision. Understanding the pathways to EHCP and EOTAS – again totally ignored. We have to navigate it ourselves. I spend so much time helping other parents who have been abandoned. On the pathway to diagnosis no-one tells you about SENDIASS, EHCPs etc. The Cluster seem to be the first port of call and we all laugh about it being the 6-month denial stop off that parents are abandoned in.
- Follow up support, appointments to discuss the emailed report, signposting to support services, knowledge of what we don't know yet, useful tips and ideas.
- There is no ongoing support, through my new job role as a disability employment adviser I am learning daily about other conditions such as dyspraxia, reasonable adjustments, neurodiversity. It would have been helpful to have information relating to these. Especially as my child is in an Academy that is very positive disciplined based and 100% attendance. Getting the Academy to stop comments each lesson and thus detentions for slow pace = executive functioning. Organisational skills, lateness to a lesson after PE etc.
- What help is available to parents, EHCPs should be done as soon as if it's written on the diagnosis advice.

**In the long term, is there anything that you think could be put in place that could make things better/easier for you and your family?**

- I think more support should be offered via professionals instead of parents having to fight for everything.
- The CAHMS assessment took 28 months from when I referred her, the school having refused to refer her, so the length of time was just ridiculous. I referred her at the start of Year 5, and she received her diagnosis halfway through Year 7.
- We have been under 3 different consultants for co-existing conditions, but no-one is an expert on autism and these presentations. I have to start at the beginning every time and feel that I am just labelled as a fussy mother. We are then discharged with no follow-up as things are not classed as acute or linked together. We have spent hours in A&E departments with soft tissue injuries that don't really need to go to A&E but as J has an autistic view on pain we cannot tell if there is a bony injury or not so need to get it checked out. A medical team that is specialised in autistic co-morbidities would be so good and probably save resources in the long run. The urology team at Dewsbury have been the best at working with us but we will be discharged from them soon as J is 16. Our GP practice is large, and we rarely speak to the same person. J has been put on a whole ream of medication that has turned out either to be not suitable for her or made things worse. During lockdown we have had no f2f appointments with them which, for an autistic who doesn't communicate over the phone, has been very difficult.

- Some sort of a package of support for parents of newly diagnosed children that directs to info on DLA, EHCP, therapies that may help, peer group and individual support for the child, and of course increased funding for the peripheral support groups and advocacy services as well as for SEND in school and CAMHS.
- Flowcharts of support and accessing support
- SENCOs are the current gatekeepers of everything. Parents of neurodivergent kids, especially kids who are academically able, are ignored, and kids are forced to experience trauma. This often leads to EBSN (what schools call school refusal). This leads to so many mental health conditions which could be supported so much earlier. SENCOs just say – oh they're fine. I have personal experience of that happening to both of my children, and literally hundreds of other parents it happened too. There needs to be far greater understanding of what Autism actually is, how it presents, and bringing in Autistic voice to that so that SENCOs are not so dismissive and consider what's happening for a child. Yes, they may look fine, but if a parent is having to dress them in bed and the child is in turmoil when school is mentioned – that's a massive signal to potential SEND. Don't ignore it. If it was the other way around and a child didn't want to go home, we'd be seeing all manner of support coming in, but because it's a school for some reason we think it's Ok for abuse to take place there because it's for educational purposes – it's not!
- Access to EOTAS needs to be made far higher up on the agenda. So many parents and kids effectively off-rolled because LCC does not make parents aware of this option. Yes it's expensive but so is treating mental health issues in adolescents and adults which result from EBSN. Far better to provide education otherwise and avoid this. I currently have a complaint in as the 2019 LGO ruling which said the main services which support children and young people with additional needs needed to work harder together, put mechanisms in to prevent children from drifting, and create a child missing education for medical needs policy in place. They didn't. I've asked everyone and no-one knows it exists, and if it does – SENDIASS, EHE and CME depts don't know about it. Inexcusable!
- Parents being listened to and placed as equitable in the process is essential. I had a case worker recently get very cross with me – an Autistic adult with 2 Autistic / Dyslexic / Dyspraxic children that was I saying he didn't have as much understanding as me because he didn't have lived experience. Yes, yes that's exactly what I'm saying. How on earth could he? How would that be an acceptable thing to say to a black parent of black children!! We have to stop treating neurodivergence and learning differences as less!!! And that starts at the centre.
- Schools need better training and support. Neurodivergence is a protected characteristic under the Equalities act. Schools don't seem to realise this. They seem to think that they can say children won't when it is children can't. They wouldn't say this about a wheelchair user – they wouldn't say a paraplegic won't use the stairs, they would say can't, and neurodivergent children should be given the same respect. My child is discriminated against daily by adults who should know better, who have a stereotypical view of what Autism is, and who think that by forcing and keeping barriers in place, they can make my child do something he actually can't do. They think because he looks like he can do it, he can do it. It's shameful! More parents need to be empowered to stop this happening to their children. The level of trauma it creates, and the mental health issues are huge and inexcusable.
- Parents should be supported to understand what neurodivergence looks like in children and young people. A friend of mine who clearly has two Autistic kids currently has one out of education for over a year, and the other for a half term. She has been passed from pillar to post, she has no idea of the services which can help, she has been referred to cluster who are as much use as a chocolate teapot, but who also doesn't really know what Autism is and has a very outdated view – so broaching it is really difficult from a parent-to-parent perspective. Her youngest child has recently transitioned to secondary school and I had a work with the SENCO to say, look this family is being abandoned. It's clear what's going on, I can see it you must be able to see it can't you help? And the SENCO to be fair to him, did broach it with the parent and referred to CAMHS. How can

that be the process by which a child and a family are removed from crisis! A parent sees what's happening, uses the influence and knowledge they have to get things moving. Not on! Not on at all!

- And then when a child is out of school LCC leave them to drift. I'm currently counting each day and sending an email to the council with the day out of education. I have a formal complaint in. We're on day 29. If I'd have taken my child out of school for 29 days would the attitude have been so lax? No, I'd have been issued with at least one fine and sent all manner of threats by school and by the education attendance team. But apparently, the law only comes into force from one side. The need to deliver education otherwise by the LA at 15 days is being ignored, and unless a parent knows the law and pushes for it, that situation seems to remain indefinitely. In addition, schools would be hard placed to deliver an EHCP remotely for any child – let alone an academically able Autistic child. They'd need to provide a fully bespoke offer that would probably be home tutors (online often just doesn't work for many Autistic kids). At that stage, the school setting becomes untenable because no-one would count that as a reasonable adjustment and most parents would be looking to say school can't meet need. As such, the LA has a legal responsibility to step in. What happens is, the LA tied to force the school to deliver – the school can't – and so the child is left. In the meantime, the parents try to force the LA to deliver the legal rights and the LA ignored the law and let the child drift, while using everything they can to delay it – we don't have enough medical evidence for example – when in fact they absolutely do have more than enough evidence and parents and child voice backing up EOTAS, they just don't want to action it. And so, ignore their legal duties and allow the child to remain outside of education.
- There is a huge lack of awareness of the academic ability of Autistic kids. My eldest is at Priesthorpe which is meant to be one of the leading lights for Autistic kids in the city – heaven help us. Yes, they understand to an extent how to support the sensory needs – but we're not just one dimensional, and many Autistic people are also very academically able, but often only in one or two key areas. We also like to concentrate on what we're good at and interested in. The curriculum doesn't like that. Schools don't like that/ But the law is clear – kids can be disapplied from subjects and should supported to achieve to the best of their abilities – not some predetermined human construct of age related.
- In addition, there is little concert about how Autistic people share their knowledge and understanding. It's often difficult to do this in written form. But schools don't get that. Sats are discriminative – there is not online paper – yes you can use a lap-top but you have to add an extra layer of processing for a child do that as they have to create the answer paper themselves. School is set up for written work – written processing, many Autistic people will share their thoughts differently. They need to be supported to and not just through oh here's a laptop or here's a scribe, but through how to formalise thoughts etc. Many Autistic people have huge knowledge in specific subjects, they need to be supported to share this in essay form earlier than their peers – but instead they are presumed less competent and less knowledgeable. This leads to huge lack of self-esteem and boredom. And in some cases bad behaviour which is totally misunderstood.
- Potential Plus UK and the DME Trust are seeking to change this – but schools have no concept of DME – Dual and Multiple exceptionality. This is harming so many off our children. They don't understand that our kids need to be taught differently and they arrogantly assume they know our kids better. I've currently had to put into place a tutor from a local uni so that my child can learn on a par with an expert and this is really helping his self-esteem, but school don't even recognise this need.
- PDA – no-one in schools gets what this is. Parents don't know what this is. There are so many adult PDAers out there – Kirsty Forbes Harry Thompson, out there sharing their knowledge – school refusal – Emotionally Based School Non-attendance and DME should be something that is considered an expectation of any Autistic child who presents as also academically able / intelligent. Just anyway. We shouldn't be waiting for these kids to be put through trauma, to experience PTSD because of schools and the adults

who should be helping them, before we act. And when this trauma happens, we should be recognising that it's the adults that have to change not the kids.

- We should just always be approaching this as how to we ensure an accessible, equitable education for Autistic children and young people. But we don't. Look at how EHCPs are written by SENCOs and case workers, for example "x struggles to engage with peers and needs support to better develop friendships"! No, x doesn't!!! x finds it difficult to relate to neurotypical peers but is perfectly content with other neurodivergent peers. What x struggles with is an understanding of the nuances and hidden meanings in the way neurotypical people communicate. What x needs is support in understanding how neurotypical people communicate, how to engage with them, and how to celebrate and accept their authentic Autistic selves. They do not need to have written into the very plan that is meant to support their physical and mental health as a child and young person the need to assimilate into a neurotypical or adapt to meet the adults in their lives. They need the barriers removed and them to be recognised as a different neurotype.
- Schools need to understand – if you discriminate against a neurodivergent person, that is exactly the same as discriminating against a disabled person. Exactly. The. Same. If you refuse to access that an Autistic person says they can't do something, they mean can't, not won't, and then go on to humiliate them and refuse to remove the barriers to them accessing learning, that is discrimination. There's no defence to this. If you say, we just need x to learn how to write their thoughts down so that we can assess them, you may as well say to a wheelchair user, we just need x to learn to walk up the stair so they can access their English class. Not OK! Not ever Ok! Happens to my child on a daily basis! I asked him today, do you feel the discrimination happens all the time – hi answer? It depends on who the adult is. And we wonder why we have a mental health crisis. And this is with a child who doesn't present with bad behaviour because it's the only way they can advocate their needs – what happens to those kids? PRU and prison? My kids advocated for himself last week – he said no loudly to a teaching assistant who was outright discriminating against him. The school tried to impose sanctions on him for this. They are so blinkered in what it is to be an Autistic young person, so authoritative (and may Autistic kids especially PDAers do not go with authority – respect is earned – authority is a neurotypical construct which makes no sense) and his is at a school who supposedly understand Autism – absolutely no way!!!
- The fact that many schools are still driving the Autism awareness agenda at the absolute odds to the Autistic Community is a huge issue. We all know about Autism – we don't need awareness, we need acceptance, acknowledgment and understanding. So many workplaces, especially in tech and culture and the third sector, are now aligning to this. We get that neurodivergent skills are crucial to our workplaces and the future. And that traditional barriers such as focus on curriculum or skills rather than specialisms, written applications, verbal interviews are all outdated. Not putting the right adjustments in outdated. Yes, schools still do this all the time – they say it's to make kids work ready but they don't know what that is – they don't know what the workforce actually looks like. And they don't ask. And they also forget that they should be advocating for the workforce to change and remove barriers, not simply getting kids to assimilate. We've had so many examples of access to extra-curricular stuff being through routes which have barriers to Autistic and other neurodivergent kids. I call it "acceptable discrimination" now, because schools accept that they are discriminating without batting an eye lid. Would this be OK with any other protected characteristic community. Of course, it wouldn't, so why is it when we talk about neurodivergence? So many adults, so many teachers, still have biased stereotypical mindsets about these kids – and it has to change.
- I could probably say more here, you get my drift. I should not have to have an effective PhD in Autism and neurodivergence, have built it into my working life, and have a full understanding of the legal regulations and application in order to be able to advocate for my child to access an equitable education. Neither should I have to spend the equivalent of a full time job doing this to ensure my kids access and equitable education. Yet both

are true. And finally, I shouldn't spend much of my time supporting other parents who've are being equally abandoned and yet I do.

- Good follow up support, clear information readily available, next steps guide, useful reading list.
- We are applying for parental EHCP. Access to an advisor post diagnosis to talk through support options and an acceptance that you have a disabled child, and that the child receives support too.
- Yes, an EHCP to assist my child. I have now lost confidence in the system and the educational system for my child. No one ever seems to be on the same page. You have to fight for everything they need, proving their worth, proving you're not making up their needs. It's exhausting.

### **Other comments collected by SENDIASS through the private Facebook Group**

My son was diagnosed with ADHD in March and Autism in August and we haven't heard anything from anyone in terms of support or services to turn to.

I think any support after diagnosis is hugely lacking! I also think there needs to be some major support in place for parents who haven't got a clue about autism or adhd or the effects on the person who is ND. I was massively underprepared before doing all my own research. Someone needs to reassure parents new on the pathway that they aren't crap parents and there's likely something else going on

I'll make contact for the questionnaire but surely most of the faults are already known, but still not fixed. E.g., referred for Cygnet August 2020 - no updates or anything since then.

We've just come to the top of cygnets list 2 1/2 years later

I have 2 boys both diagnosed with autism. One was diagnosed at 2 using the early intervention, the support and information offered for him was amazing. I was offered as many courses as we wanted, help to learn Makaton, parent courses, stay and plays and opportunity's to meet parents in similar situations... they were faultless in their support..... then my oldest was diagnosed at 5, 2 years after his brother using CAHMS and there was no follow up or offers of anything, we were just given a leaflet ... just to say the courses we were offered for my youngest were all very preschool based due to his age so they weren't very useful when my oldest was diagnosed.

I feel that there is literally next to no support before, during or after diagnosis.

The process of expressing concerns is daunting and you feel like a nuisance making requests for referrals. You're often bombarded by 'professional' jargon which makes you feel inadequate. Ultimately services need funding to provide support at all stages as well as to tackle the waiting lists, to employ more staff and train them well.

It might be incorrect, but I was recently told that a SENCo has several years to complete training for the role and I feel this is terribly inappropriate... you would not allow a 1st year medical student to perform major surgery so why would someone not fully trained be placed in a position in charge of a child's special educational needs and disabilities?

There needs to be more clear direction about what is available. Schools/nurseries, colleges/Drs surgeries need more information available on their websites, reception etc that is jargon free or explains the jargon appropriately.

The best support I have received has been online, usually on Facebook from West Yorkshire ADHD Support Group.

The group is predominantly ADHD related however they understand the crossover of diagnoses and the care, knowledge, guidance and support from this group is what has got me, as a single

parent to kids- 7year old boy ADHD, autism and an 18 year old girl ADHD and complex SEMH needs through the last 2 years.

I'd completely agree that, once you've waited for years to actually get to the top of the list to be assessed, it feels like you're just handed a diagnosis and told to go away. As if that fixes all the problems because now there's a nice, neat label to attach to it. We were told parental support in Leeds is great once you get to the top of the list to go on the "training": 14 months later we've heard nothing else

More support for parents! It would have been nice to have more support and help in place for now 11 year old son. Only recently diagnosed. The whole process to get him help. Has been a nightmare!

I'll happily fill in a questionnaire. It's ridiculous you fight for years to get a diagnosis, can't get any support without a diagnosis, get the diagnosis to be put on another 2yr waiting list for CYGNET training and any STARS referral at school, by the time you get there the course is useless because you've learned it all yourself the hard way and needed all that information whilst you were still trying to get the diagnosis

Noticed your comment via my dad about experience of being a parent with an autistic child. And the process of diagnosis and help. Please can I be part of it. As I have had to fight over 10 years for help and finally got a diagnosis but are still on the list for his mental health assessment. The process of CAHMS needs to be stripped apart and redesigned. If it wasn't for help from individuals heaven knows where my son would be now.

---