

Preliminary Report Regarding Autistic School Refusal/Non-Attendance and Links to Trauma

Introduction

This report contains basic preliminary data following the launch of our survey entitled ‘Autistic School Refusal/Non-Attendance and Links to Trauma’. The survey, which has been shared on social media and our website, received an extraordinary amount of responses within the first 48 hours, and this report contains a summary of that data.

The survey will remain open until Sunday 3rd January 2021. A full report of all data will be published on our website by the end of January 2021. As noted in the survey, participants can withdraw their responses up to, and including, Sunday 3rd January 2021 by emailing info@autisticuk.org quoting their memorable five digit number. The survey is anonymous, and IP addresses have not been logged. Participants confirmed that they consented to undertaking the survey, and a list of support services was included on the final page due to the sensitive nature of the questions we were asking.

We created the survey for a number of reasons:

1. We are told that the way non-attendance is framed by professionals is often starkly different to how it’s described by Autistic people and/or their parents.
2. We want to establish what the catalysts to non-attendance are in order to inform our work in this area.
3. We want to establish what support (if any) is in place prior to non-attendance.
4. We are often told that school is a direct cause of trauma for Autistic people, yet it is not included in the list of Adverse Childhood Experiences (ACEs). We want to find out if this experience is as wide-spread as it initially seems.

Limitations

Our preliminary analysis has indicated that there are some limitations to the data collected, and prior to compiling our full report we will seek to address them. These include:

- Large drop off. This could be for a number of reasons including people changing their minds and accessibility. In order to address accessibility issues, we are looking into having alternative methods of collecting information from those who wish to participate including video calling and email.
- The experiences of some participants not fitting into the categories listed. This is likely to cause understandable frustration, and those participants should be able to inform us of their experiences if they would like to. Therefore, the aforementioned alternative methods of collecting information will allow these stories to be told.
- Fewer Autistic people are answering than parents of Autistic people. This could be due to the nature of the survey; however, we would like to hear from more Autistic people

directly prior to the publication of our full report. We will speak directly with the community to find out what we can do to increase participation.

- We have very few responses from the Black and Ethnic Minority communities. Prior to our full report we will actively engage with, and seek out responses from, these communities to ensure their voices are heard.

Preliminary Findings

Our survey to this point was started by 278, however as mentioned in the limitations there was a large drop off. We didn't make any questions compulsory as this is a sensitive topic and some questions could be potentially triggering. On average, each question had 183 respondents, with a large number providing additional information. This preliminary report will be made up of straightforward statistical data, with more in-depth analysis and quotes from respondents due to be included in our full report which will be produced by the end of January 2021.

We had 20 Autistics complete the survey on behalf of themselves (10.81%) and parent/carers totalled 165 (89.19%).

Setting

We first established what educational setting the Autistic young person attended prior to non-attendance. This is to establish whether setting contributes to non-attendance and the age ranges at which non-attendance starts.

Setting	Total	%
Mainstream Nursery (3-4)	4	2.17%
Mainstream Primary (4-11)	78	42.39%
Mainstream Secondary (11-16)	89	48.37%
Mainstream Sixth Form/College (16-18)	2	1.09%
Specialist Primary (4-11)	7	3.8%
Specialist Secondary (11-16)	4	2.17%

No respondents indicated that the Autistic young person was in a specialist nursery or specialist sixth form/college.

This indicates that the vast majority of Autistic young people are in mainstream education prior to non-attendance.

Support

We asked respondents to indicate what support was put in place prior to non-attendance, and what was put in place to support the Autistic young person during time out of a formal educational setting.

Support	Prior Total	%	During Total	%
Educational Psychology	22	12.02%	35	18.92%
Occupational Therapy	14	7.65%	17	9.19%
Speech and Language Therapy	14	7.65%	14	7.57%
1:1 Support from a Teaching Assistant	24	13.11%		
Child and Adolescent Mental Health Services	40	21.86%	76	41.08%
Social Services	2	1.09%	27	14.59%
No Support	90	49.18%	59	31.89%
Attendance Officer			55	29.73%

We also asked respondents to let us know of any support received that was not included in our list. Responses included:

Support	Prior Total	%	During Total	%
Special Educational Needs Coordinator/Additional Learning Needs Coordinator	2	6.45%		
Social and Emotional Mental Health Services	1	3.23%		
Autism Outreach	1	3.23%	1	7.14%
Specialist National Autistic Society School	1	3.23%		
Key Worker	1	3.23%		
Exit Card	1	3.23%		
Private Psychologist	1	3.23%	1	7.14%
Early Support/Help	1	3.23%	1	7.14%
Family Support Worker/Services	2	6.45%	1	7.14%
Special Educational Needs Support (Sometimes via a plan)	3	9.68%		
ELSA	1	3.23%		
Nurture	1	3.23%		
Paid-for literacy support	1	3.23%		
EHCP	1	3.23%		
Waiting lists with no support	3	9.68%		
ACT	1	3.23%		
Adoption Support Therapy	1	3.23%		
Art Therapy	2	6.45%		
Mind 1:1 Sessions	1	3.23%		
Outreach from Specialist School	1	3.23%		
Specialist Teacher Input from Local Authority	1	3.23%		
Play Therapy	1	3.23%		

IEP	1	3.23%		
School Nursing Team	1	3.23%	1	7.14%
Private Wellbeing Practitioner	1	3.23%		
Children’s Services	1	3.23%		
Parent Training			1	7.14%
Access to Education Team			1	7.14%
NAS Educational Psychologist			1	7.14%
Local Authority Teaching and Learning Provision			1	7.14%
Flexible Learning from Early Help			1	7.14%
Therapy			1	7.14%
KIND – Kids In Need of Development			1	7.14%
Autism Team			1	7.14%
School Counsellor			1	7.14%

Almost half of our Autistic respondents and the Autistic young people parent/carers responded on behalf of were completely unsupported in school prior to their non-attendance. This reduced – though not dramatically – to 31.89% during non-attendance. It is demonstrative of the reactive approach to support, yet the Equalities Act states that when it comes to reasonable adjustments the [duty on schools is ‘anticipatory’](#)^[1]. That only 12.02% of Autistic young people were seen by Educational Psychology prior to non-attendance, and with that rising to only 18.92% during non-attendance, is shocking, and indicates that schools are not attributing potential or actual non-attendance to emotional, social, or learning difficulties. It could, however, also be reflective of the common practice of schools having a set number of Educational Psychology visits allocated to them annually, which is reflective of school size rather than the needs of the pupils.

Some respondents informed us that support was withdrawn prior to non-attendance, with others reporting that EHCPs were in place, but were not written robustly and were therefore ineffective in identifying and meeting the support needs of the Autistic young person.

Support received during non-attendance was often funded by parents, or were initiated by the EHCP application process. Others report that there was ‘no real help for school non-attendance’ and that they ‘wrote to them all begging for help [...] and not one bothered to get back to me’.

Reasons for Non-Attendance

This question was asked to identify the different reasons for non-attendance that were identified. We asked what the Autistic or parent/carer were told by school/professionals were the reasons, and what they themselves identify as the catalysts for non-attendance.

Reason	School/Prof Total	%	Autistic Total	%	Parent/Carer Total	%
Sensory Processing Differences	33	18.13%	11	57.89%	122	72.19%
Non-Compliance	51	28.02%	2	10.53%	3	1.78%
Anxiety	97	53.30%	15	78.95%	162	95.86%
Depression	14	7.69%	7	36.84%	49	28.99%
Other Mental Health Condition	7	3.85%	3	15.79%	20	11.83%
Bullying	6	3.30%	7	36.84%	38	22.49%
Self-Esteem	22	12.09%	11	57.89%	83	49.11%
Transition – both within the school day and from one school to another	29	15.93%	9	47.37%	94	55.62%
Difficulties with Staff	23	12.64%	7	36.84%	87	51.48%
Demand Avoidance	35	19.23%	4	21.05%	92	54.44%
Academic Pressure	8	4.40%	6	31.58%	70	41.42%
Overprotective Parenting	64	35.16%			1	0.59%
Trauma	12	6.59%	9	47.37%	81	47.93%

We also asked if there were reasons other than those listed. We were informed of the following:

Reason	School/Prof Total	%	Autistic Total	%	Parent/Carer Total	%
Poor Parenting/Lack of Discipline	12	6.60%				
Being Autistic	3	1.65%			1	0.60%
Blaming the Child – Saying ‘it was on purpose’ or ‘wilful refusal’ or ‘naughty’	6	3.30%				
No issue – ‘fine’	4	2.20%				
Separation Anxiety	2	1.10%				
Illness	1	0.55%				
ADD	1	0.55%				
Difficulties with Friends/Peers	2	1.10%			1	0.60%
Copying Sibling Behaviour	1	0.55%				
Exhaustion from Masking/ Burnout/Shutdown	1	0.55%	1	5.26%	3	1.80%
School Wouldn’t Disclose	2	1.10%				

Difficulty Accessing the Curriculum	1	0.55%				
Emetophobia			1	5.26%		
Not Meeting Academic Expectations			1	5.26%		
Not Accommodating Needs/Not Being Listened To	1	0.55%			9	5.39%
Attendance Pressure					1	0.60%
Eating, Drinking, and Bathroom Issues (incl. Chronic Constipation)					3	1.80%
Physical Health					2	1.20%
Teachers Shouting					1	0.60%
Sexual Assault on Premises					1	0.60%
Multiple Teachers					1	0.60%

There is a stark difference in the way schools/professionals attribute reasons for non-attendance and the experiences of the Autistic young people and their families. While only 18.13% of schools/professionals attributed sensory processing differences as a contributing element in non-attendance by the Autistic young people, over half of Autistic respondents and nearly three quarters of parent/carers identified this as a factor.

More worryingly, schools/professionals are more likely to blame parent/carers or the Autistic young person themselves – even if this was indirectly – by citing non-compliance, overprotective parenting, poor parenting, and outward blame of the child in far greater numbers than Autistics and parent/carers.

Trauma, which is identified as a factor by almost half of our Autistic and parent/carer respondents was only attributed to non-attendance by 6.59% of schools/professionals.

Describing Non-Attendance

We asked respondents to tell us how the term ‘school refuser’ made them/their Autistic young person feel if this was the term used by school and/or professionals. This question was asked openly, however responses were categorised in order to create this preliminary report.

How It Made Them Feel	Total	%
They were doing something wrong/it was their fault/a choice	42	28.77%
Autistic young person is unaware/parent/carer protected them from it	5	3.42%
Upset/angry as it’s not the right phrase – it’s not a deliberate ‘refusal’	25	17.12%
School anxiety or barriers to access would be better	9	6.16%
They didn’t use that phrase	18	12.33%
More anxious about getting into trouble with authorities	4	2.74%

Like a failure	5	3.42%
Judged	1	0.68%
Sick with worry	1	0.68%
Belittled	1	0.68%
Like Aliens	1	0.68%
Like you have to choose between education and wellbeing	1	0.68%
Scared	1	0.68%
Suicidal	4	2.74%
Sad/Awful/Bad	7	4.79%
Anxious	1	0.68%
Misunderstood/Unsupported/Dismissed	4	2.74%
Inadequate/Stupid/Repressed	3	2.05%
Autistic young person didn't care	1	0.68%
Victimised	1	0.68%
Confused	1	0.68%
Let Down	2	1.37%
Guilty/Ashamed	5	3.42%
Like it was easy to sort out	1	0.68%
The term doesn't initiate emotion – it's the delivery	1	0.68%

As you can see, 'school refusal' is the term used by most school/professionals, with only 12.33% not using the term. However, the language used to describe non-attendance by Autistic young people is directly contributing to their mental ill health. 28.77% said that it made them feel like they were doing something wrong; like it was 'their fault' or a 'choice' not to attend. A further 17.12% said that they were upset and angry with the term as it's 'not a deliberate refusal'.

Language is important, particularly in childhood. The language used around – and directed at – children stays with them and contributes to the building up, or breaking down, of self-esteem and self-worth. Language which apports blame to the Autistic young person and/or their parents/carers not only damages their wellbeing, but it also removes responsibility from the school/professionals in making school accessible.

We then asked if another term was used, what it was and how it made them feel. These responses will be integrated into our full report in January, however a couple of responses stood out, and we felt it was important to include the verbatim quotes in this preliminary report:

*“Violent Unacceptable behaviour Dangerous Mental health condition
Permanent exclusion How did this make me feel: sad, enraged by la for
putting him in a setting without the adequate assessments, broken hearted
as felt I had lost part of my child, determined to support him. Alone”*

*“My son was labelled as naughty and that just lowered his self esteem
further and as his mum being labelled a neurotic parent when I knew that*

wasn't the case was heartbreaking I felt that I was fighting a fight I was never going to win"

"Manipulative and spoilt."

""The wrong person in the home is making the rules" implying that my child was deciding what was happening. Made me feel inadequate, misunderstood and no longer wanting to try with the school."

"In general, the school used a whole host of behaviorist terms which made me feel as if they had no interest in understanding the real reasons my child was struggling, and which made my child feel constantly evaluated, for good or bad"

"Unable to attend due to poor mental health. I'm happy with this description providing there is an understanding that the main driver for poor mental health is school and the lack of empathy, understanding and support to my daughter."

"The normal, bad behaviour, do want your parents to go to prison. The normal crap."

These quotes demonstrate that even when different terms were used, the language which describes the non-attendance of Autistic young people often blames the Autistic young people and their families, with no ownership being retained by schools/professionals.

Returning to Education

We asked how/where the Autistic young children were educated post non-attendance.

Education Setting	Total	%
Returned to current school with support	20	10.64%
Returned to current school without support	14	7.45%
Transferred to another school – mainstream with support	5	2.66%
Transferred to another school – specialist setting	21	11.17%
Educated Other Than At School	16	8.51%
Home Educated – Deregistered	32	17.02%

Other settings which we were informed about include:

Education Setting	Total	%
Private Tutors	4	5.00%

Alternative Provision – Outdoor School/Home Education Groups etc	4	5.00%
Currently Looking for Alternative Placement	3	3.75%
Unofficially Home Educated due to education authority not meeting needs	7	8.75%
Unable to Attend	32	40.00%
Requested EOATS	2	2.50%
LA refusal to provide alternative education	14	1.75%
Part Time School	2	2.50%
Private School	1	1.25%
College	2	2.50%
School Unit Attached to Mental Health Unit	1	1.25%
Non Maintained Specialist School	1	1.25%
Base in Mainstream School	1	1.25%

It is a minority of Autistic young people who have had periods of non-attendance who return to mainstream school without support – 7.45% of respondents. 40% are unable to attend school but are not receiving any other provision, with a further 1.75% having been refused alternative education provision by their Local Authorities. Only 31.92% of Autistic young people, whether they are supported and/or specialist settings or not, return to state schools.

We suggest that this is indicative of reactive responses to supporting Autistic young people in school, and the difficulties faced by parent/carers and schools alike in obtaining funded support – via EHCPs in England and Statements and/or Funded Healthcare Plans in Wales. While the ‘expense’ of these legal education plans are often quoted as reasons not to assess – as are arbitrary rules regarding academic attainment – the cost to local authorities and the NHS in funding out of school tutors, EOATS provisions, additional Educational Psychology, inpatient care, and mental health support etc. is far greater than that of proactive properly funded and appropriate support. The cost to the Autistic young person’s wellbeing when school placements fail is far greater again.

Impact on Mental Health

We wanted to establish the impact of school on the Autistic young person’s mental health. Again, this was an open question, but responses fall into the following categories.

Impact	Autistic Total	%	Parent/Carer Total	%
Suicide Attempts including inpatient care in psychiatric hospitals	2	11.76%		
Suicide Attempts – no inpatient care	1	5.88%	4	2.33%
Suicidal Ideation			11	6.40%
Self-Injurious Behaviour/Self-Harm			11	6.40%
Traumatic/PTSD	3	17.65%	35	20.35%
Poor self-esteem and confidence	4	25.53%	23	13.37%
Eating Disorder	1	5.88%	3	1.74%
Unable to Attend School/Phobia	1	5.88%	9	5.23%

Negative/Detrimental/Deterioration	5	29.41%	54	31.40%
Sense of Failure	1	5.88%	2	1.16%
Increased Anxiety/Stress			44	25.58%
Terrified/Scared			7	4.07%
Enhanced Fight/Flight/Fawn Response			3	1.74%
Low Mood/Depression			16	9.30%
Withdrawn/Isolated			9	5.23%
Burnout/Shutdown/Exhaustion			2	1.16%
Selective Mutism			2	1.16%
Obsessive Compulsive Disorder			2	1.16%
Angry			7	4.07%
Trust Issues			7	4.07%
Panic Attacks			4	2.33%
Insomnia			2	1.16%
Intrusive Thoughts			1	0.58%
Tic Disorder			1	0.58%
Unable to concentrate			1	0.58%

We separated the data provided to indicate responses which came directly from Autistic participants and those which were provided by parent/carers. This is so that Autistic experience is highlighted.

It is stark to see how many Autistic young people have attempted suicide as a result of attending school. 3.7% of the Autistic young people had made an attempt, and a further 5.82% have suicidal ideation. In light of the [rising suicide rates in under-25s](#)^[2] this should be of great concern.

Self-harm, poor self-esteem, increased anxiety, and depression are all commonly experienced by the Autistic young people. Trauma/PTSD is also experienced by 20.11% of the Autistic young people in this survey. As PTSD is experienced by [approximately 3% of the UK population](#)^[3] the figure from our survey is alarmingly high.

Positives

We asked if there were any positive supports put in place. These will be fully disseminated in our full report in January; however, we have provided a breakdown of the number of families who received positive supports vs those who did not:

Support	Total	%
No	69	46.62%
Yes	75	50.68%
Family Paid/Arranged	6	4.05%

It's roughly a 50/50 split between those Autistic young people who were provided positive support during their period(s) of non-attendance, and those who were not. We would suggest that it is unreasonable to expect any child who is not attending school due to accessibility

issues due to their support needs not being met to return without any support. This lack of support also indicates the issue raised in the way non-attendance is framed, and how this promotes unhelpful attitudes to the Autistic young people and their families by school/professionals.

Effect of COVID-19 Pandemic

We asked respondents to indicate whether the COVID-19 pandemic had caused further difficulties for the Autistic young person in accessing school-based education with a particular focus on the transition back to school after the initial lockdown.

Transition Struggle	Total	%
Yes – attend with more support	18	11.61%
Yes – attend with no change to support	16	10.32%
Yes – attend with no support	8	5.16%
Not attending	84	54.19%
No struggle	23	14.84%
Attending Hospital School	1	0.65%
Attending Specialist School	2	1.29%

Over half of the Autistic young people in this portion of the survey are not attending school post lockdown. Anxiety surrounding COVID-19 has affected many people across the UK, and children are no different. The Autistic young people whose experiences are featured in this survey were already in a heightened state of anxiety, trauma, and distress. The added concerns from the pandemic is making accessing a school-based education more difficult, and pressures placed on already limited services mean that waiting lists for support are growing.

Physical Health

Many Autistic people report that they have co-occurring physical health conditions which exacerbate their ability to manage day-to-day demands and expectations, including school. We asked respondents if their Autistic young people have any physical health conditions which contributed to their non-attendance.

Does the Autistic young person have a physical health condition?	Total	%
Yes	38	22.22%
No	131	76.61%
Prefer Not To Answer	2	1.17%

We then asked what physical health conditions the Autistic young people have to get a better understanding of the additional barriers to accessing school-based education.

What Condition?	Total	%
Respiratory	2	5.71%
Fatigue	3	8.57%

Anaemia	1	2.86%
Abdominal Migraine	1	2.86%
Epilepsy/Seizure Disorders	3	8.57%
Migraines	4	11.43%
Skin Conditions	1	2.86%
Recurring Infections	2	5.71%
Allergies/Intolerances	3	8.57%
Hypermobility/Connective Tissue Disorders	11	31.43%
Sleep Disorders	2	5.71%
Autoimmune Conditions	4	11.43%
Gastrointestinal Conditions	4	11.43%
Chronic Pain	2	5.71%
Brain Conditions	2	5.71%
Kidney Conditions	1	2.86%

The most common reported co-occurring physical health condition was hypermobility/Ehlers Danlos Syndrome with 31.43% of Autistic young people who have a physical health condition being affected. This is followed by migraines, autoimmune conditions, and gastrointestinal conditions, each with 11.43% of Autistic young people who have a physical health condition being affected.

All conditions indicated by respondents have the potential to make accessing education in a school setting difficult, particularly if unsupported.

We also asked if the school accepted that that these physical health conditions contributed to the Autistic young person’s difficulty in attending education settings.

Accept?	Total	%
Yes	20	25.64%
No	47	60.26%
Prefer Not To Answer	11	14.10%

Most respondents indicated that school/professionals did not accept that the Autistic young person’s physical health condition contributed to their non-attendance. This further undermines the experiences of those Autistic young people, and is likely to exacerbate relational difficulties with the education settings, and detrimentally affect their mental health.

Conclusion

This preliminary report indicates that there is a stark difference in what is attributed to the non-attendance at school by Autistic young people. Respondents indicate that schools/professionals are more likely to attribute behavioural issues which suggest ‘fault’ lies with the Autistic young person and/or their parent/carers. Autistics and their parent/carers, however, are more likely to attribute sensory processing difficulties, mental health conditions, and lack of support.

It is clear that schools/professionals don't often consider trauma when discussing non-attendance, yet this is often experienced by the Autistic young people, and can lead to self-harm, suicidal ideation, and suicide attempts.

Even when Autistic young people have become unable to attend school, support is not forthcoming, and many parent/carers are having to source external support, some of whom are paying for private assessments and tuition.

We acknowledged the limitations of current data, and will address these prior to generating our full report in January 2021. This preliminary data indicates the need for wide-scale participation to ensure we have a full picture prior to publication.

URLs

[1] <https://publications.parliament.uk/pa/ld201516/ldselect/ldseqact/117/11708.htm>

[2] <https://www.samaritans.org/wales/about-samaritans/research-policy/suicide-facts-and-figures/>

[3] <https://patient.info/mental-health/post-traumatic-stress-disorder-leaflet>