

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

Introduction

This is our full report following the analysis of the data gathered in our survey entitled 'Autistic School Refusal/Non-Attendance and Links to Trauma'. The survey was shared on social media and our website, and received a relatively high number of responses.

The survey was completely anonymous, and IP addresses were not logged. Participants confirmed that they consented to undertaking the survey, and contact details of support services were 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 explore the catalysts to non-attendance are in order to inform our work in this area.
3. We want to reveal 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 could be as wide-spread as it initially seems.

Limitations

Our analysis has indicated that there are some limitations to the data collected. These were highlighted in our preliminary report, and despite our endeavours to address them, some remain. 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 informed our stakeholders that we could conduct video interviews and/or accept emails containing information regarding the topic in lieu of the survey, and that their details would remain anonymous in all reporting. We had no requests for alternative collection methods.
- Fewer Autistic people are answering than parents of Autistic people. This could be due to the nature of the survey; however, we sought additional responses from the Autistic community, though there is still a disparity.
- We had very few responses from the Black and Ethnic Minority communities. We actively engaged with, and sought out responses from, these communities, however this was with limited success.

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Findings

Our survey was started by 375 participants, however as mentioned in the limitations there was a large drop off (though only one Autistic respondent). 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 245 respondents, with a large number providing additional information.

We had 25 Autistics complete the survey on behalf of themselves (10.04%) and parent/carers totalled 224 (89.96%).

Setting & Support Prior to Non-Attendance

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.

Mainstream Nursery (Age 3-4)	2.02%	5
Mainstream Primary (Age 4-11)	45.16%	112
Mainstream Secondary (Age 11-16)	46.37%	115
Mainstream Sixth Form/College (Age 16-18)	1.21%	3
Specialist Primary (Age 4-11)	3.23%	8
Specialist Secondary (Age 11-16)	2.02%	5
		248

As with our preliminary report, no respondents indicated that the Autistic young person was in a specialist nursery or specialist sixth form/college. Our data indicates that the vast majority of Autistic young people are in mainstream education prior to non-attendance.

“Mainstream just don't get what support should be there unless put in a legal document.”

Respondents advised us of the supports which were 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.

We also provided space for respondents to inform us of any support settings which were not included in our list. These entries have been grouped into categories and added to the tables. Note that some respondents received more than one support service, therefore percentages are based on number of responses received.

	Prior		During	
Educational Psychology	11.34%	28	19.28%	48
Occupational Therapy	8.50%	21	8.84%	22

Speech and Language Therapy	8.10%	20	6.43%	16
1:1 Support from a Teaching Assistant	16.19%	40	0.00%	0
Child and Adolescent Mental Health Services	21.86%	54	37.75%	94
Social Services	2.43%	6	13.25%	33
Attendance Officer	0.00%	0	25.30%	63
No Support	46.15%	114	36.14%	90
Children's Services	0.40%	1	0.00%	0
Early Intervention	0.40%	1	0.40%	1
EHCP/Statement	0.81%	2	0.00%	0
Family Support Worker	0.81%	2	0.00%	0
In-School Support	5.26%	13	0.00%	0
LA Specialist Teachers	2.43%	6	0.00%	0
Mental Health Support	2.83%	7	1.20%	3
My Plan/School Action Plus	0.81%	2	0.00%	0
On Waiting Lists	1.62%	4	0.40%	1
School Nursing Team	0.40%	1	0.00%	0
Self-Funded Specialist	2.43%	6	0.00%	0
Support Withdrawn	0.40%	1	0.00%	0
Alternative Provision	0.00%	0	2.01%	5
Autism Outreach	0.00%	0	0.80%	2
Behaviour Attendance	0.00%	0	0.40%	1
Charity/3rd Sector	0.00%	0	1.61%	4
Family Services	0.00%	0	0.40%	1
Inclusion Team	0.00%	0	0.40%	1
Medical Referral	0.00%	0	2.41%	6
Parenting Course	0.00%	0	0.80%	2
Welfare Officer	0.00%	0	0.40%	1
		247		249

“I made a formal complaint to the school regarding how she was treated and because we hadn't had the full autism assessment they made out that it was all me and implied FII.”

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 36.14% 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 11.34% of Autistic young people were seen by Educational Psychology prior to non-attendance, and with that rising to only 19.28% during non-attendance, is shocking, and may indicate 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 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 ascertain the different reasons attributed to non-attendance. 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.

Again, we provided space for respondents to inform us of any reasons which were not included in our list. These have been grouped into categories and added to the tables.

	School / Professionals		Respondents	
Sensory Processing Differences	16.73%	41	67.74%	168
'Non-Compliance'	27.76%	68	3.63%	9
Anxiety	52.65%	129	93.55%	232
Depression	8.16%	20	31.45%	78
Other Mental Health Condition	5.71%	14	12.10%	30
Bullying	3.67%	9	22.58%	56
Self-Esteem	11.43%	28	50.81%	126
Transition - within the school day and/or from one school to another	17.14%	42	51.61%	128
Difficulties with Staff	13.47%	33	52.82%	131
Demand Avoidance	18.78%	46	50.00%	124
Academic Pressure	5.71%	14	42.34%	105
'Overprotective Parenting'	29.80%	73	0.81%	2
Trauma	7.35%	18	48.39%	120
Autism	1.63%	4	2.42%	6
Assault	0.00%	0	0.40%	1

Burnout	0.41%	1	2.02%	5
Cognitive Difficulties	0.82%	2	0.00%	0
Copying Sibling	0.41%	1	0.00%	0
COVID Anxiety	0.82%	2	0.00%	0
Family Breakup	0.00%	0	0.40%	1
Phobia/Panic	0.00%	0	0.40%	1
Attachment Issues	0.00%	0	0.40%	1
No Reason	6.94%	17	0.00%	0
Physical Health	1.22%	3	2.42%	6
Poor Parenting	8.98%	22	0.00%	0
Separation Anxiety	0.41%	1	0.00%	0
Social Difficulties	0.82%	2	0.81%	2
Suicide Attempt	0.41%	1	0.00%	0
Trauma	0.41%	1	0.00%	0
Unsupported Needs	0.82%	2	9.27%	23
Wilful Refusal	2.04%	5	0.00%	0
		245		248

We also asked if respondents had any further information they'd like to add regarding the reasons for non-attendance. 147 respondents provided details, and key words were attributed to the descriptions. Though many responses provided further details regarding the issues in the table above, there were a number of reasons not previously mentioned:

Eating Disorder	0.70%	1
Exclusion/Seclusion	4.93%	7
Forced In	2.11%	3
Had to Home Ed	2.11%	3
Lack of Trust	2.82%	4
Masking	4.93%	7
Overwhelm	5.63%	8
Suicidal Ideation	0.70%	1
Self-Harm	0.70%	1
Undiagnosed Barrier	6.34%	9

“If more support was given at the beginning many children/YP's MH wouldn't deteriorate so badly and there would be a far better outcome all round.”

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 16.73% of schools/professionals attributed sensory processing differences as a contributing element in non-attendance by the Autistic young people, 67.74% of our respondents identified this as a contributing factor.

“[I’m] being cruelly Safeguarded for FII by this particular school. Munchausen is another big issue.”

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 7.35% of schools/professionals.

It is also suggested that schools/professionals are less likely to consider anxiety a factor in an Autistic young person not attending school, 52.65% compared to 93.55% of respondents. It is possible that the risk of non-attendance is exacerbated by the lack of understanding and acknowledgement of the risk factors by professionals within the educational system.

More positively, only 3.25% of respondents were fined as a result of the Autistic young person not attending school. Though we do not condone any fines, it is pleasantly surprising that the figure isn’t higher, and is indicative that schools are possibly more aware of the reasons for non-attendance than is discussed with the Autistic young people and/or their parent/carers. However, there is also an indication that fines were avoided due to parent/carers being pushed into de-registering their Autistic child, and home educating them.

“Found the school extremely unsupportive and the threats of constant fines and court was too much and that’s why deregistered.”

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, and the 188 responses were categorised in order to create this report. The table excludes responses indicating that the school and/or professionals did not use the term.

Attempted Suicide	0.67%	1
Blamed/Judged/Guilty	48.32%	72
Depressed/Low	10.74%	16
Frustrated/Angry	16.78%	25
Negative	2.68%	4
Okay/Neutral	3.36%	5
Low Self-Esteem	14.77%	22
Parent Protected the Child	3.36%	5
Stressed/Anxious	8.05%	12
Suicidal Ideation	2.01%	3
Unsupported/Unheard	15.44%	23
		149

'School refusal' is the term used by most school/professionals, with only 20.74% not using the term. However, the language used to describe non-attendance by Autistic young people is directly contributing to their mental ill health. 48.32% felt blamed by the school; that non-attendance was a choice. The term directly impacts on their wellbeing, with three Autistic young people having suicidal ideation and another attempting suicide as a result.

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, making them feel **'Vile. Worthless. Crazy. Abused.'** but it also removes responsibility from the school/professionals in making school accessible.

We also asked if another term was used, what it was and how it made them feel. Responses included both positive and negative entries. We received 84 statements so we are unable to provide all answers verbatim, but the following highlight the importance of language and attitudes on the wellbeing of the Autistic young people:

Positive:

“So far, school is supportive and recognise the issue as anxiety related and that she is unable to return until the underlying issues are resolved.”

“We had ‘educated off site’ term used. This helped my child feel it was ok to work from home when needed.”

“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.”

Negative:

“I was repeatedly told I was responsible for getting him into school. I felt they thought I was being irresponsible. I was frightened, depressed, and very angry. I thought we would get help. I was wrong.”

“Breaking the law made me feel I was going to get fined or have social services think I was a bad mother”

“Making bad choices’ - very discouraging and unhelpful.”

“A doctor wrote a note and the school agreed for me to have a part time timetable due to me having M.E. none of it made sense to me and nothing explained the underlying feeling that I was different. It felt horrible and I felt like an outcast.”

“Manipulative and spoilt.”

“‘Truancy’ made me feel uneasy and misunderstood because when people say that it’s usually referring to those who have ‘bunked off’ without parents’ permission and are hanging around having fun rather than being at school whereas I was at home struggling with lots of intrusive thoughts.”

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.

Returned to current school with support	11.07%	27
Returned to current school without support	9.02%	22
Transferred to another school - mainstream with support	3.28%	8
Transferred to another school - mainstream without support	0.82%	2
Transferred to another school - specialist setting	10.25%	25
Educated Other Than At School (EOTAS)	8.61%	21
Home Educated - Deregistered	20.08%	49
Alternative Provision	8.20%	20
Change in Staff	0.41%	1
College	0.82%	2
Unable to Attend	26.23%	64
Mental Health Support	0.41%	1
Reduced Attendance	2.46%	6
Self-Funded Support	1.23%	3
Tuition	1.64%	4
		244

A minority of Autistic young people who have had periods of non-attendance return to their current mainstream school without support – 9.02% of respondents, with many indicating that they and/or their Autistic young person is/was officially home educated, educated other than at school (EOTAS) or unable to attend school (56.56%). Only 36.89% of Autistic young people, whether they are supported, full or part-time, and/or in specialist settings or not, return to state schools.

This may be indicative of reactive – rather than proactive – 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 identify the potential impact of school on the Autistic young person’s mental health. This was an open question so as not to lead responses and to allow the respondents to give as much – or as little – information as they wanted. Responses were categorised based on content, with those which did not provide details other than ‘bad’ or ‘negative’ being groups as ‘Negative Impact – Not Specified’.

	Parent/Carer		Autistic	
Abandonment	0.46%	1	4.76%	1
Anxiety	28.11%	61	14.29%	3
Breakdown	1.38%	3	0.00%	0
Depressed/Low	13.82%	30	9.52%	2
Dissociated	0.46%	1	0.00%	0
Eating Disorder	1.38%	3	4.76%	1
Hospitalised	0.46%	1	9.52%	2
Irritable/Angry	4.61%	10	9.52%	2
Isolated	3.69%	8	0.00%	0
Life Ruined	3.69%	8	0.00%	0
Low Self-Esteem	19.82%	43	47.62%	10
Meltdowns	1.84%	4	4.76%	1
Negative Impact - Not Specified	24.88%	54	23.81%	5
Not the School	0.46%	1	0.00%	0
OCD	0.92%	2	0.00%	0

Overwhelmed	3.69%	8	0.00%	0
Physical Manifestation	2.30%	5	0.00%	0
Resilient	0.46%	1	0.00%	0
Risky Behaviour	2.30%	5	0.00%	0
Routine of School Positive	0.00%	0	4.76%	1
Selective Mutism	0.92%	2	0.00%	0
Self-Harm	5.53%	12	4.76%	1
Sleep Disturbances	3.23%	7	0.00%	0
Suicidal Ideation	6.91%	15	4.76%	1
Suicide Attempt	2.30%	5	9.52%	2
Tics	0.46%	1	0.00%	0
Trauma	18.43%	40	23.81%	5
Trust Issues	8.29%	18	4.76%	1
Wished They Were Never Born	0.46%	1	0.00%	0
Withdrawn	11.06%	24	0.00%	0
		217		21

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

“I have suffered from mental health issues since I was 8 yrs.”

It is stark to see how many Autistic young people have attempted suicide as a result of attending school. 2.94% of the Autistic young people had made an attempt, and a further 6.72% have suicidal ideation. Further analysis of these figures reveal that of the 21 Autistic young people who had suicidal ideation and/or had attempted suicide, 8 were of primary school age (4-11), and 13 of high school age (11-16). 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 18.91% 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. While the survey title is likely to attract responses from those who are more likely to have experienced trauma, we still feel that this figure warrants further investigation.

To elevate Autistic voices from our survey, we have included some of the response we received (verbatim) to the question which informed the above table, ‘What impact has school had on your mental health?’

“School had a positive impact on my mental health in terms of providing structure and routine. It also positively fulfilled my need to learn and think. However, it caused a lot of anxiety in terms of socialising and created a feeling of alienation from my peers, it was overwhelming on a sensory level that often left me anxious, irritable, and prone to meltdowns, and as the workload increased and my executive dysfunction became more pronounced I became more depressed and hopeless, with feelings of abandonment and invisibility. A decade later I still feel depressed, hurt, and anxious about how my absence was treated.”

“I was traumatised. The experiences repeated themselves throughout my time at school.”

“Huge and lasting negative impact and has contributed to my development of c-ptsd.”

“2 suicide attempts in 9 months, 5 months in 4 different hospitals, hundreds of miles from home.”

“Lead me to suicide attempts and set harm, PTSD, and ended up being an I patient at many psychiatric hospitals.”

“I had very low self-esteem throughout my school years, resulting in a period of having an eating disorder, and suffered intense anxiety and depression, which is still present today. I'm also very intimidated by figures in authority (particularly women - the teacher in question who bullied me was a woman), to the point where I will still actively avoid situations involving them, such as walking past security guards, managers, police, assistants with 'severe' expressions etc. Certain situations, such as a P.I.P assessment, can trigger intense memories from school and cause me to meltdown/shutdown. I have therefore speculated whether I might have complex PTSD.”

“School is the #1 cause of the deterioration of my mental health. The combination of bullying, lack of acceptance, academic pressure due to being ‘gifted’, victim blaming, refusal to adapt and general treatment from staff and services almost turned out to be fatal.”

While these statements are distressing to read, it is important to highlight the impact that the education system can have on Autistic young people; an impact which has lasting effects on their adult lives.

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Positives

While many of our questions related to potentially negative experiences faced by the respondents and/or their Autistic young people, we also asked if any positive supports were put in place by school to assist with their attendance. These can be initially broken down into yes/no responses:

No	42.86%	90
Yes	57.14%	120
		210

While the number of 'yes' responses have increased since our preliminary report, there's still a large number of Autistic young people who were not provided positive support during their period(s) of non-attendance.

Further evaluation of the data revealed a theme among those who had indicated that there *had* been positive supports put into place: though they were validating, they were too little too late, and were often withdrawn.

Positive supports have included **'sensory breaks, the use of resistance bands, using a card to show when [they] need a break as [they're] too overwhelmed to speak, and [encouragement] to go to the toilet,'** and **'alternative provision [...] run by people who really understood mental health issues and [autism] [...] making them] feel understood and provid[ing] a safe and supportive environment.'** However, support is often only provided after crisis, including hospital admission and tribunals.

We would suggest that it is unreasonable to expect any child who is not attending school due to their needs not being met and/or school being inaccessible 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. Please note that the survey closed prior to the latest lockdown, during which time most schools were open.

We filtered out any responses indicating that their children were not attending school prior to COVID-19 lockdown as this question specifically targeted those Autistic young people who were attending school. This is to ensure that responses are directly linked to – or have been directly exacerbated by – COVID-19.

Yes - attend with more support	13.66%	25
Yes - attend with no change to support	13.66%	25
Yes - attend with no support	4.37%	8
Yes - not attending	38.80%	71
No	16.39%	30
COVID not the issue	0.55%	1
Different Setting	4.37%	8
Remote Attendance	0.55%	1
Struggle To Attend	0.55%	1
Tried to Attend – Now not attending	2.19%	4
Variable Attendance - No Support	3.28%	6
Variable Attendance - With Support	1.64%	3
		183

40.98% of the Autistic young people in this portion of the survey are not attending school post lockdown, with a further 6.01% either being educated remotely, or attending school sporadically. 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. Our stakeholders are also indicating that the uncertainty surrounding schools being open – and whether or not they will close again – is particularly difficult for Autistic pupils.

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 they (if responding themselves) or their Autistic young people have any physical health conditions which contributed to their non-attendance:

Yes	22.22%	54
No	76.54%	186
Prefer not to answer	1.23%	3
		243

“[X] had a buggy for long walks but school wanted us not to use it as it drew attention to [them] and the other children may make fun of [them] still using a buggy.”

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

Allergies	6.12%	3
Autistic Burnout	2.04%	1
Autoimmune	10.20%	5
Autonomous Nervous System	2.04%	1
Blood Disorders	2.04%	1
Chronic Illness	2.04%	1
Connective Tissue	24.49%	12
Epilepsy/Seizure Disorder	10.20%	5
Fatigue	6.12%	3
Gastro-Intestinal	14.29%	7
Hearing Loss	2.04%	1
Hormone Imbalance	2.04%	1
Kidney Condition	2.04%	1
Migraine	8.16%	4
Muscular Skeletal	12.24%	6
Neurological	2.04%	1
Pain	6.12%	3
Parent Disabled	4.08%	2
Periodic Fever Syndrome	2.04%	1
Physical Symptoms of Mental Health	2.04%	1
Recurring Infections	4.08%	2
Respiratory	4.08%	2
Skin Conditions	2.04%	1
Sleep Disorder	4.08%	2
Undiagnosed	2.04%	1
		49

The most common reported co-occurring physical health condition were those relating to connective tissue, such as Ehlers Danlos Syndrome and Hypermobility Spectrum Disorder with 24.49% of Autistic young people within this survey who have a physical health condition being affected. This is followed by gastrointestinal conditions, muscular-skeletal conditions, autoimmune conditions, and epilepsy/seizure disorders, which affect 14.29%, 12.24%, 10.20% and 10.20% of Autistic young people who have a physical health condition, respectively.

“The school have raised the fact that I am autistic (Asperger’s) as a potential safeguarding concern to LA and disclosed my private medical diagnosis- no previous concerns ever mentioned before undertaking complaints procedure.”

The responses also draw our attention to parental disability potentially making accessing school more difficult, particularly when their child is in distress. This is a sensitive point, however, as many parent/carers are wary of disclosing their own disabilities due to the prejudices they face as a result.

All conditions indicated by respondents have the potential to make accessing education in a school setting difficult, particularly if unsupported. Therefore, we asked if schools accepted that that these physical health conditions contributed to the Autistic young person’s difficulty in attending education settings.

Yes	25.93%	28
No	55.56%	60
Prefer not to answer	18.52%	20
		108

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.

Summary

This report indicates that there is a stark difference in what is attributed by schools/professionals to the non-attendance of Autistic young people, and what they and their families experience. 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.

Our data suggests 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. It has also been indicated by our stakeholders that school is often dismissed as the cause of trauma experienced by Autistic young people when the issue is raised with mental health professionals.

Even when Autistic young people have become unable to attend school, our analysis of the data suggests that support is not forthcoming, and many parent/carers are having to source external support, some of whom are paying for private assessments and tuition. This reported lack of support, and comments from respondents, also indicate that the high percentage of Autistic children who are being educated at home – whether officially or not – is due to a lack of alternatives rather than it being a choice. This could further marginalise these families as one or more parent/carer(s) are forced to give up paid employment and/or reduce their hours, together with the expense of self-funding tuition and specialist services, potentially pushing them into poverty. In turn, the stigma associated with not being in paid employment can further isolate these families.

“I don't think she will ever be able to go back. I have had to leave my job to look after her at home because she is making no progress towards being able to return at all.”

We acknowledge the limitations of our data and analysis, and would welcome academic research in this area. There is very little literature, despite non-attendance of Autistic pupils being a relatively well-known issue, with the two most prevalent studies in library searches coming from Japan and Norway. The lack of research, and the limitations of what is currently published, is highlighted in [Totsika et. al. \(2020\)](#)^[4].

Recommendations

Following the results of our survey, we recommend the following:

- Further research into the reasons for non-attendance of Autistic pupils, focussing on Autistic experiences.
- Targeted research into the experiences of further marginalised Autistic non-attenders, including those from Black and other Ethnic Minority Groups.
- The inclusivity of the education system is re-evaluated, with a particular focus on mainstream schools identifying what can change (attitudes, sensory environments, staff training, etc.).
- School is formally identified as a possible source of trauma for young people, particularly those who are Autistic.
- Consideration is made for those Autistic pupils who are unable to attend mainstream settings, particularly those whose academic profile screens them out of specialist settings.
- A proactive approach to support is instigated, with local education authorities held accountable when this approach is not undertaken.

“There needs to be smaller schools for children with anxiety, especially secondary schools. My child would rather die than attend mainstream secondary.”

URLs

- [1] <https://publications.parliament.uk/pa/ld201516/ldselect/ldagact/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>
- [4] <https://journals-sagepub-com.libezproxy.open.ac.uk/doi/10.1177/1362361320916967>