

# Issues in persistent non attendance at school of autistic pupils and recommendations following the reintegration of 11 autistic pupils

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## Editorial comment

Catrina is a specialist teacher and an educational consultant and trainer who supports many schools and nurseries in Wales and the South West of England and is the founder of Neuroteachers, a training and coaching company for educators. In this paper, she argues that official data shows that autistic pupils in the UK often have periods of prolonged absence from school. Staff are keen to help pupils back into school, but Catrina argues that there is rarely 'a quick fix' and that it can be helpful to think in terms of the pupil having a serious injury or physical illness, where staff would not expect a quick return to school. Triggers for non attendance may be a specific incident or the result of longer term social exclusion or feelings of failure. Worries about home and family members might also contribute and so a thorough analysis and understanding of the issues contributing to their non attendance needs to be made. Catrina and others believe that autistic pupils are often traumatised by their experiences and so using trauma informed approaches can be successful. She presents a case study to illustrate the points she makes and adds to this with details of ten other persistent non attenders. This paper fits well with the Accept Approach described by Aaron Yorke in this issue of the *GAP Journal* and the paper on bullying by Mary Ellen Huxter. Taken together, these serve to give ideas on what might be helpful.

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## Acknowledgements

Thanks to Jodie Smitten, Cathy Wassell, Michelle Faulkner, Victoria Kamm and Quinn Dexter for your support with this project.

Permission was given by all subjects and their parents, where appropriate. All names have been changed and any other identifying features have been removed.

This research was self funded.

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## Introduction

Data from the Department for Education (DfE, 2019a) suggest that approximately 1.7 per cent of the English school population is autistic. The majority of autistic pupils (Billington, 2019; DfE, 2019a) attend mainstream schools or settings. The DfE data (2019a) also show that around 11 per cent of the total school population display 'persistent absence' (PA). Schools that do not achieve an overall attendance rate of over 95 per cent trigger an automatic OfSTED (Office for Standards in Education)

visit (OfSTED, 2020) so staff are keen to address persistent non attendance.

PA is defined as missing at least 10 per cent of all school days during a given period (usually all the possible days to attend in an academic year between September and July in England). According to the charity Not Fine in School data (2020), this amounts to almost 80,000 pupils per school year. This charity's data also suggest that up

to 40 per cent of such children and young people (CYP) are either autistic, are awaiting a diagnostic assessment for autism or have a related, communication and interaction condition (eg Social Communication Disorder, Developmental Communication Disorder, other unidentified Speech, Language and Communication Disorder). Similarly, the DfE (2019a) has reported that 43 per cent of those with PA are autistic.

The reasons that autistic learners are at greater risk of PA include communication differences, their sensory profile, and their needs and difficulties with transition. To be successful in a mainstream setting, autistic pupils may mask their behaviours or hide their special interests to appear more neurotypical. This may be stressful and over time, may result in autistic fatigue and burnout ( National Autistic Society, 2020). Burnout can also lead to trauma, as described in a survey conducted by the research charity, Autism UK in 2020.

### **Terminology relating to attendance**

Systematic data collection is not easy and so attendance data may not give the full picture. First, there are 32 different ways of registering absence in England (DfE, 2019a) and second, there are at least 24 different terms for children and young people (CYP) who do not attend school (Heynes et al, 2019). For the purposes of this paper, the terms 'Anxious Non Attender' (ANA) will be used to describe autistic CYP who are unable to attend school, and the term 'Persistent Absence' (PA) will be used for the time CYP are unable to attend school, due to factors which do not include medical appointments, illness, behaviour based exclusion, truancy or parental withdrawal. The author feels these terms accurately describe the potential reasons for non attendance in autism and do not have such negative connotations as other terms used.

The "Autistic UK" survey (2020), for example, found that autistic young people and their parents feel that many of the terms used to describe both ANA and PA are highly negative to the point of causing mental health issues and suicidal ideation. Heynes et al (2019) list terminology describing PA in England from 1932 to the present day. Much of the language is derogatory and judgemental (*eg mother-phile; Masquerade syndrome;*

*stay at home neurosis; school refuser*). This is not conducive to good relationships between schools, paraprofessionals, the autistic pupil and their families. Language is an important aspect. As has often been discussed by autistic individuals, the language used plays an important part in an individual's view of themselves and their identity.

The exact number of autistic absentees is hard to discern as no full data sets exist. The data in this study has been gathered from several sources including three surveys from charities (Autistic UK 2020; Not Fine in School, 2020; Autistic Girl's Network, 2020) and from DfE data (2019a; 2019b), and one recently peer reviewed paper (Totiska et al, 2020). Further studies would be useful to understand the scale of this issue.

This paper will look at the data that is available, together with the author's own data, collected over five years and examine common themes to find solutions to this all too common problem.

### **The cost to society of Persistent Absence**

Totiska et al (2021) state that PA leads to a 28 per cent increase in school dropout. PA students are also at increased risk of socio economic problems, unemployment, mental health issues, self harm, and drug misuse (Breed et al, 2017; Goodall 2018, Hancock, 2018). As with other forms of exclusion, children who have PA in childhood have a greater need of tax funded, public services in future. It is hard to measure the factors such as the waste of talent, the financial costs and the emotional strain on the family but these are considerable and avoidable if different steps were taken to support those who find attending school a challenge.

### **Recent research**

Although the issue of PA presents educators and parents alike with a deal of concern, there is limited research into this area in relation to autistic pupils (Totiska et al, 2020). There has been a significant increase in the number of ANAs generally according to Government statistics (DfE, 2019a). Since the Covid 19 pandemic, the problem of school based anxiety has increased due to uncertainty caused by lockdowns and returning to school while the virus is still in circulation

(Dove, 2020). These findings by Dove came from a survey of 1,516 students in London in mainstream and special schools. Although this was a survey to glean attitudes from among the whole school population, the sample size contained 26 autistic learners from mainstream and special schools. The results showed that all learners were keen to get back to school (54 per cent), and 56 per cent were anxious about the social aspects of returning (Dove, 2020).

Over the last five years, prominent parent support groups such as Not Fine in School and Square Peg have risen in popularity on social media. The autism research charity, Autistic UK, carried out a survey in 2020 to find out more about school based trauma and its effect on autistic learners. This anonymous survey of 245 parents and autistic pupils explored the difference in perspective between parents/autistic learners and educators. The charity wanted to examine the causes of PA in autistic learners, the support available and the possibility that school based trauma is widespread among autistic people. They found that professionals did indeed attribute blame for behavioural issues with the autistic learner or their family and that autistic learners and their families pointed to sensory or mental health issues or a lack of support as the root cause.

There is evidence that two thirds of autistic learners have negative school experiences (Breed et al, 2017; Goodall et al, 2018). PA is a significant factor in early school dropout (Schoenberg, 2012), mental health issues and socio-economic issues in later life (Hancock et al, 2013). Yet the most recent peer reviewed article on the topic (Totiska et al, 2020) lists just two studies; Kurita et al (1991) from Japan and Munkhaugner et al (2017) from Norway, looking at this issue in any depth. Totiska et al's (2020) data show that medical absence is 23 per cent more prevalent amongst autistic learners than it is among peers. The issue of PA is an increasing problem internationally, according to the International Network for School Attendance (2020). Although this organisation does not look specifically at autistic PA, they note that the overall problem of PA is increasing, particularly in wealthy, industrialised nations such as America, Northern Europe and Japan.

Parental withdrawal of their child from school, either short term, or to home school, is often a reactive consequence of either PA or fixed term exclusions (Autistic Girls Network 2020, Autistic UK 2020). Although one understands the reasons for parents electing to take their child out of school, it is not in their interest longer term as where parents take their child out of school voluntarily, then the local authority no longer has a responsibility or duty to provide education for their child.

### **Adjustments deployed to promote the attendance of ANA pupils**

There are several 'reasonable adjustments' that school staff often make for autistic children who have PA. These adjustments include temporary changes to the timetable, giving an exit card, creating a buddy system, encouraging the child to go to school and having a trusted member of staff to meet the child at the school door. Some schools may employ an Emotional Literacy Support Assistant (ELSA) or set up other social skills or support groups. However, although such adjustments may help some autistic pupils, these are often not sufficient to encourage and enhance the attendance of many autistic pupils, especially those who have been absent for some time.

### **Reasons for the lack of success of current measures**

The reasons for this lack of success are twofold. First, these adjustments are often short term and often used sporadically as part of a 6–8 week cycle. Recommendations from the three charities (Not Fine in School 2020, Autistic UK 2020, Autistic Girls' Network 2020) suggest that a programme of reasonable adjustments can take a minimum of a year to be successful. Secondly, staff and others may look at just one barrier to attendance. They might focus on social issues or generalised anxiety and may fail to take into consideration other socio-economic, ethnic, gender or other issues such as bullying (Totiska et al, 2020). There may be a lack of understanding of autistic masking or of hiding difficulties which can lead to burnout and trauma (NAS, 2020).

## Effective approaches to support ANA pupils

Currently, surveys and studies suggest that there are three key areas to consider to design an effective strategy for an autistic ANA. First, there needs to be effective collaboration between the school, other involved agencies, the parents and the pupil. Secondly, sufficient time is needed for changes to happen (up to one year on average) and thirdly, holistic approaches which are both relational and trauma-informed need to be used.

### Trauma informed approaches

Trauma informed approaches (TIA) require an understanding of attachment theory (Bowlby 1969) which describes four main attachment styles: secure, anxious, avoidant, and disorganised, (Ainsworth, 1969). Schools using TIA, aim to develop a young person's secure attachment with staff to prevent potential mental health difficulties.

A study by Harrison et al (unpublished, 2021) with the Alex Timpson Trust involves a 5 year, longitudinal study with 300 schools. All the staff, including midday supervisors, are offered training in Trauma-Informed Approaches. Evidence from continuing study suggests that this training leads to improved outcomes for vulnerable learners. Parker and Leinson's (2018) review of literature about TIA noted that these educational methods improve motivation among vulnerable learners. There is also evidence from a review of 5 years of TIA in Derbyshire Schools which showed substantial changes to ethos and practice led to better outcomes for vulnerable learners (Kelly, Watt and Giddens 2017).

### Relational Practice

Relational Practice involves seeking to have a mutual relationship of '*unconditional positive regard*' and is based on the work of humanist psychologist, Carl Rogers (1960). Rogers believed in a person centred approach and that all behaviour is goal directed to satisfy needs. He wrote that distressed behaviour signals that needs are not being met. Many schools embed this ethos into their culture and find that it has a significant impact on distressed or concerning behaviour (Dix, 2019). Whittaker (2021) explains that using such an approach has a positive effect on all students and is particularly effective in supporting vulnerable students.

## A case study

Here I describe the process of re-integrating an autistic, Year 7 girl into a large mainstream comprehensive school in the South West of England after a three month period of absence. I then summarise the features in common with 10 other autistic students who have been successfully re-integrated (see *Appendix 1*).

Victoria (fictitious name) was an autistic, Year 7 student (aged 11 at the start of the study) of average to above average intellectual ability. She attended a mainstream, urban, secondary school. She was diagnosed with autism, aged 5 and dyslexia, aged 7. She had coped well in primary school without an EHCP and was part of a large cohort of students who had an enhanced transition to secondary school. Her transition had gone well, and Victoria appeared content at the school. She had a Teaching Assistant (TA) with enhanced training in autism who acted as her keyworker. Victoria enjoyed Art and had joined several lunchtime clubs including Arts and Crafts and the Anime club, through which she made friends with a small group of girls, and another autistic pupil. Staff felt that this was a positive friendship.

Victoria liked to be neat and tidy and always wore her uniform with pride. She became upset if any dirt or paint got on her clothes. During February of Year 7, a 'sickness bug' was going around local schools. Victoria contracted this illness and vomited in her tutor's classroom at break time. The tutor acted swiftly and called her parents to collect her. Victoria recovered from the bug within 48 hours, but was scared to return to school for two reasons. First, she was concerned that fellow students had seen what had happened and would 'find her disgusting', even though she had been alone with her form tutor and TA at the time of the incident. Secondly, she was concerned about the infection re-occurring.

When Victoria was still unable to attend school a week later, the Head of Year, who had been in constant contact with Victoria and her parents, made a home visit and planned to re-integrate her into school. His plan involved brief visits on consecutive mornings, followed by three days of attending only Music, Art, and Drama (her favourite subjects), followed by full attendance the following week.

At home, Victoria had agreed to all the above, yet in practice she was unable to carry these out because she still felt anxious. The SENCO then became involved and made a referral to a specialist teacher (the author).

### **Adjustments made for Victoria**

The author met with Victoria and her parents at the family home. Her key worker was also present and together they discussed what they felt were the key barriers to her attendance. Her parents had gone as far as disposing of the soiled school uniform and buying Victoria a new one

It transpired that there were important domestic factors that contributed to the situation. Victoria's father had lost his job very recently. He had found a new job but it involved a long commute. Victoria's grandmother had also been ill for over a year.

Victoria said that to attend school again she would need to be able to sit in a classroom unseen by her peers. She also wanted to wear a pink wig in the corridors so that other students would not recognise her. The author arranged for both things to happen.

Victoria spent several weeks going into school for one hour a day, sitting in the learning support classroom on her own doing either Art, Music, or Drama work and wearing her pink wig. After around a month, her key worker introduced her closest friend into the room where Victoria had been working, and the two girls worked together on an Art project. Following that, Victoria went outside into the Year 7 playground with her chosen friend every day for 15 minutes after their lesson together. This was at a time when no other students were out of class. After two months, Victoria was able to attend school for up to 2 hours each morning, doing Art, Music or Drama with one of five friends. Victoria looked out of the window at break and lunch-times to observe what other children were doing in the playground.

After three months, Victoria was able to briefly join her peers for up to 5 minutes in the playground, minus

the pink wig. After six months, she went to an English lesson to hear her friends do a presentation about Frankenstein's Monster. She then attended afternoon registration and Music, Art or Drama lessons with her peers. By the end of Year 7, Victoria's attendance had improved to around 75 per cent. Her timetable was still bespoke with an hour at the beginning of every day doing an Art, Music or Drama project with a friend of her choice. She attended some lessons including Maths, English, Science and French, intermittently, and was able to catch up with work at home during the afternoons if she could not attend school.

During the summer holidays, the keyworker and SENCO had weekly touch base sessions where they emailed or telephoned Victoria to see how she was. There was also a home visit by both members of staff in the final week of the holiday. Victoria started Year 8 by following the same pattern as at the end of Year 7. This continued for the first month, then she felt ready to start attending more subjects. By the end of Year 8 she was attending around 90 per cent of lessons and went to school for 95 per cent of school days.

### **Staff training**

Prior to the reintegration programme, the author delivered whole school training on autistic masking, burnout, and trauma. All key staff also attended a student clinic about Victoria. This was run by the author and Victoria's key worker and consisted of a 20 minute briefing explaining Victoria's needs and likely barriers to attendance. They were careful to manage the expectations of teachers, many of whom thought Victoria should return to school within a couple of weeks. Teachers needed to understand that such a re-integration process takes time (one year on average according to Not Fine in School data 2020), but also that progress may not be linear. Victoria was recovering from a traumatic experience. Getting past this would come in peaks and troughs. Staff had an opportunity to ask questions and were given monthly updates. The staff accepted the management plan and took pains to make Victoria feel welcome in school, by contacting her directly. This was usually via email but five members chose to use video links to speak to Victoria, as this was prior to the pandemic.

## Work with other Autistic ANA Students

*Appendix 1* gives key information on ten other students who struggled to attend school on a full time basis. I gathered data to look for common features in their profiles. The participants ranged in age from 9 to 16 years. The group included one non binary pupil and two transsexual individuals. All went to mainstream primary or secondary school, which included a private secondary school. Asthma (n=2) and hypermobility (n=3) were the most common physical comorbidities. All participants had comorbid neurodiverse (ND) conditions including ADHD (n=5), Dyslexia (n=6), Dyscalculia (n=3), Demand Avoidance (DA, n=5), Dyspraxia (n=1) with some pupils having more than one related ND (n=7). Mental ill health was also common with 8 CYPs having clinical levels of anxiety (n=7), depression (n=5) or avoidant/restrictive food intake disorder (ARFID, n=1) and self-harm (n=1). Of these eight pupils, five had more than one mental health need. The most common social issue to arise was peer to peer bullying (n=7) with the only other social reason listed being that their best friend had moved away.

Parental information revealed that three CYP in this data set had both parents at home, four families included one biological parent and a step-parent and three were single parent households. Only two households had unemployed adults living there. One parent was a full time student and two parents worked part time. One parent listed here as 'homemaker' had chosen to give up work to support her child through their period of PA. One parent had a medical condition (Multiple Sclerosis) and seven parents had mental health issues including either depression (n=5) or anxiety (n=1) and one had a diagnosis of bipolar disorder.

Information on their siblings showed that three pupils were only children and two had adult siblings who had left home. However, one pupil had a volatile relationship with their brother and two pupils had baby siblings who suffered ill health.

This table does not give the full range of Adverse Childhood Experiences (ACES) experienced by this cohort but does include some potentially adverse life events. The concept of ACES was first described by Felitti in 2002. It lists a series of possible life events which may induce toxic stress in a pupil. ACES experienced by the ten pupils included bereavement (n=1) poverty/ unemployment (n=3), separation (n=4), parental mental health issues (n=6), parental physical health issues (n=1) or violence from a family member in the home (1). So, all but one of the participants had experienced at least one adverse childhood experience which is likely to have added to their issues at school and contributed to their non attendance.

## Outcome for Victoria and the ten pupils

Victoria and all ten students were successfully re-integrated to school. Of these, three pupils moved to a special school or an autism resource base in their mainstream school. In each case, finding an appropriate programme of support and implementing this correctly took between 6 and 20 months. In seven cases, a bespoke timetable remained throughout their time at school. Their attendance varied from around 75 per cent (with a work placement 1 ½ days per week) to 100 per cent.

## Features in common across the schools

The two main factors which underpin successful re-integration into mainstream school are firstly, whole staff training on the implications of autistic masking and secondly, attending a school which uses a combination of trauma-informed approaches and relational practice. Staff need to support the learner and have an understanding that recovery from school based anxiety takes time. In Victoria's case, her keyworker used the analogy that Victoria's trauma was 'the emotional equivalent of breaking a limb'. This helped staff understand the seriousness and potentially long recovery time of her stress. This was almost certain to be gradual, requiring patience, empathy, and positive encouragement from staff. Success therefore also depends on staff recognising the anxiety that working with a student such as Victoria engenders in themselves, and for them to strive to avoid negativity or any hint of punishment or sanctions.



## Concluding comments

The literature on autism and PA is limited and makes few recommendations for teachers on how they might achieve long lasting attendance. Recommendations that there are, tend to go down a behavioural route and concentrate on the immediate antecedent, then look at a series of punishments and rewards rather than getting to grips with all the barriers to attendance. This has proven to be largely unsuccessful with autistic learners (Autistic UK, 2020).

Some authors suggest that those who have experienced school based anxiety often describe years of autistic masking prior to adverse events coinciding to cause the mask to slip (Smitten 2020; Belcher et al 2021; Halsall et al 2021). Masking or camouflaging means suppressing autistic traits in public. For example resisting the urge to engage in self calming behaviour such as hand flapping, rocking or pacing, often called stimming (NAS, 2020). When masking is carried out for extended periods, autistic pupils can develop autistic fatigue because of the effort required. This can lead to burnout and trauma, which may have been the case with Victoria.

With hope, this case study illustrates that when staff have some knowledge of autistic masking, and an understanding of how seemingly minor trauma can have a catastrophic effect, this facilitates planning for recovery. Recovery is most likely when there is a clear plan developed by the student, her/his family and teaching staff, who feel that they have ownership and for which sufficient non-rushed recovery time has been allowed.

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## Appendix 1: Demographic, social and economic information for ten autistic, ANA learners attending mainstream settings aged 8 to 16

Age	Gender	Ethnicity	Setting type	Comorbid physical conditions	Other neuro-diversity	Comorbid mental health condition	School based social issue?	Parents at home?	Employment status of adults?	Parental physical health issue?	Parental Mental Health conditions?	Siblings issues?
10	Male	White British	MS Primary	Hyper-mobility	ADHD/ Dyscalculia	NA	Bullying	Mother and stepfather	Employed	NA	NA	Not living at home (over 18)
16	Female	White British	MS secondary	Asthma	Dyslexia	Anxiety/ ARFID	NA	Mother and father	Employed PT/FT	NA	NA	Not living at home (over 18)
9	Male	British Asian	MS Primary	Back-ache	Demand avoidance	NA	Best friend moved away	Dad and stepmother (mother deceased)	Employed FT/PT	NA	NA	Younger siblings copy A's behaviour
14	Female	White British	MS Secondary	NA	Dyslexia	Anxiety	Bullying	Mother (divorced, no contact with father)	Employed	NA	Depression	Younger sister, no issues
8	Female	Mixed heritage (black/white British)	MS primary school	Asthma	Dyslexia/ Dyscalculia	Anxiety	NA	Mother and step-father	Student/ unemployed	NA	Depression	Baby sister- 'failure to thrive'
9	Male	White British	MS Primary School	Hyper-mobility	Demand avoidance/ Dyslexia	Anxiety	Bullying	Mother and father	Home maker / employed	NA	Anxiety	Brother also autistic. Volatile relationship with TH
16	Non-binary	White British	MS secondary	Hyper-mobility	Demand avoidance/ ADHD	Depression and anxiety	Bullying	Mother and father	Both self employed	Mother – Multiple-Sclerosis	Depression	Only child
14	Male	White Irish	Private Secondary	NA	ADHD	Depression/ self harm	NA	Father	Employed	NA	Bipolar	Only child
12	Trans male	White British	Mainstream Secondary	NA	Demand avoidance/ ADHD/ Dyslexia/ Dyspraxia	Depression	Bullying	Mother	Employed	NA	Depression	2 brothers over 18- not living at home
14	Female	Mixed race-East Asian/ White British	Mainstream secondary	NA	Dyslexia/ Dyscalculia	Anxiety/ Depression	Bullying	Mother/ step father	Employed	NA	NA	Premature baby sister
14	Trans female	Mixed race South Asian/ black British	Mainstream secondary	Asthma	ADHD/ Demand avoidance	Anxiety and Depression	Bullying	Father	Unemployed	NA	Depression	Only child