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Title: Types and correlates of school non-attendance in students with autism spectrum

disorders

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Running head: School non-attendance in ASD

Keywords: school non-attendance, school refusal, school withdrawal, truancy, school

exclusion, autism, intellectual disability

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## Abstract

School non-attendance in autism spectrum disorders (ASD) has received very little attention to date. The study aimed to provide a comprehensive description of school non-attendance in students with ASD. Through an online survey, parents of 486 children (mean age 11 years) reported on school attendance over one month, and reasons for instances of non-attendance. On average, students missed five days of school of a possible 23 days. Persistent nonattendance (absent on 10%+ of available sessions) occurred among 43% of students. School non-attendance was associated with child older age, not living in a two-parent household, parental unemployment and, especially, attending a mainstream school. School refusal accounted for 43% of non-attendance. School exclusion and school withdrawal each accounted for 9% of absences. Truancy was almost non-existent. Non-problematic absenteeism (mostly related to medical appointments and illness) accounted for 32% of absences. Non-problematic absenteeism was more likely among those with intellectual disability, school refusal was more likely among older students, and school exclusion was more likely among students from single-parent, unemployed, and well educated households. Findings suggest school non-attendance in ASD is a significant issue, and that it is important to capture detail about attendance patterns and reasons for school non-attendance.

## Lay abstract

Our study aimed to describe school non-attendance in students with autism. We conducted an online survey. Parents of 486 students (mean age 11 years) indicated which days their child had missed school (over a period of one month). If the child had missed a day, the parent was asked to select a reason from a list of 15 possible reasons (this is a measure of types of school non-attendance called SNACK [Heyne et al., 2019]). On average, students missed five days of school of a possible 23 days. Missing over 10% of school is known as persistent absence, and in our study 43% of students experienced persistent absence. Older students, who attended mainstream schools, who did not live in a two-parent household, and whose caregiver was unemployed were more likely to miss school.

Looking at the reasons for absence, school refusal was the most frequent reason, accounting for 43% of absences. Nine percent of absences were due to school exclusion. Nine percent of absence was due to school withdrawal. Truancy was almost non-existent. A final reason describes non-problematic absence that is mostly due to medical appointments and illness. This type of absence accounted for 32% of absences in our study, and it was more likely in student with intellectual disability. School refusal was more likely among older students. School exclusion was more likely among students from single-parent, unemployed, and well educated households. Findings from this study help us to understand better the difficulties students with autism experience attending school.

Missing school has a negative impact on children's academic skills (Hancock, Shepherd, Lawrence, & Zubrick, 2013) and mental health (Epstein et al., 2019). It increases the risk of dropping out of school (Schoenenberger, 2012), which in turn is linked to adverse life outcomes such as substance abuse (Townsend, Flisher & King, 2007) and mortality (Lleras-Muney, 2005). In England in 2017-2018, students missed 4.8% of all available school sessions (DfE, 2019a). Persistent absence, defined as missing over 10% of available sessions, involves one in 11 students (11.2%) (DfE, 2019a). Absence and persistent absence are at higher rates in special schools (10.2% absence and 29.6% persistent absence), and among students with special educational needs across any type of school (6.9% absence and 19.6% persistent absence: DfE, 2019a). This phenomenon of increased rates of school non-attendance in children with special needs may be exacerbated in cases where educational needs are associated with difficulties in social skills and social communication, such as those with autism spectrum disorders (ASD) (Able, Sreckovic, Schultz, Garwood, & Sherman, 2015) with rates of absence and persistent absence of 6.9% and 18.4%, respectively (DfE, 2019a).

Research on school non-attendance in students with ASD is scant, despite emerging evidence of negative school experiences that hinder these children's full participation in education (Brede, Remington, Kenny, Warren, & Pellicano, 2017; Goodall, 2018). Two studies on non-attendance in ASD populations have focused on school refusal behaviours (Kurita, 1991; Munkhaugen, Gjevik, Propp, Sponheim, & Diseth, 2017). Kurita (1991) studied school refusal in 135 Japanese children and adolescents with ASD and/or intellectual disability (ID). Parent-reported school refusal (which Kurita defined as absence from school because of child reluctance to attend in the knowledge of the parent and in the absence of antisocial behaviour) was present in 23.7% of the sample, and significantly higher among those who did not have an associated ID (Kurita, 1991). Munkhaugen and colleagues (2017)

studied 'school refusal behaviour' (SRB) using a broader definition than that for school refusal in Kurita's study including absence which others have classified as truancy rather than school refusal (e.g., Heyne, King, Tonge, & Cooper, 2001). They found that students in mainstream education in Norway with ASD (N=78) had a higher rate of teacher-reported SRB compared to students without ASD (42.6% vs 7.1%) (Munkhaugen et al., 2017). It is important to note, that unlike Kurita (1991), Munkhaugen et al. (2017) excluded children with ID. These two studies highlight the issue in available research on school non-attendance in children with ASD of substantial differences in the definition of school refusal, the methodological approach (e.g., inclusion/exclusion of ID; reporting source) and the lack of consideration of other types of non-attendance.

To fully describe school non-attendance, researchers have divided non-attendance into non-problematic (e.g., child attending a medical appointment) and problematic non-attendance (Heyne et al., 2019). A number of different criteria have been proposed for problematic non-attendance, but one of the most frequently used is missing over 10% of available sessions. This criterion is used by the UK Department for Education (termed persistent absence; DfE, 2019b) and the US Department of Education (termed chronic absenteeism; US Department of Education, 2016). At this 10% level, absenteeism has been shown to increase the risk of school drop-out by up to 28% (Shoeneberger, 2012). Heyne et al. (2019) further specified four types of non-attendance problems. School refusal refers to non-attendance linked to the youth's emotional distress associated with attending school, in the knowledge of the parent, and despite reasonable efforts by the parent to ensure the child's attendance. School withdrawal is defined as non-attendance that happens in the knowledge of the parent, but it is linked to parental effort to keep the child at home or lack of parental effort to ensure the child's attendance. Truancy refers to absence without school permission and usually involves effort on the part of the child to conceal the absence from the parents.

School exclusion refers to non-attendance that is initiated by the school either through inappropriate use of disciplinary policies, or because the school is unable or unwilling to accommodate the child's needs, or through discouragement of attendance (i.e., asking the child to stay at home). There are currently no data on school withdrawal, school exclusion, or truancy among children with ASD.

From an ecological systems perspective, school absence or non-attendance is a phenomenon that is poorly described (Melvin et al., 2019). Part of the difficulty arises because the scientific community has yet to agree on a typology for describing school nonattendance problems (Heyne et al., 2019). Related to that, school non-attendance is a complex phenomenon associated with multiple factors present at multiple levels of different systems. Melvin et al (2019) recently proposed a conceptual multi-level framework that organises the factors likely to be associated with school non-attendance across an inclusive, nested bioecological framework. The framework uses the conceptual structure of Bronfenbrenner's bioecological model to organise factors known to be related to developmental outcomes across levels of influence that differ in their proximity to the child (Bronfenbrenner & Morris, 2006). At the closest level of influence (i.e., micro and meso-system), the framework identifies child characteristics (e.g., age, gender, physical health, disabilities), parent characteristics (e.g., parent stress, physical health, parenting style, attitudes towards education), family (e.g., family composition), and school characteristics (e.g., school climate, relationships in school, inclusivity) that have been shown to be related to school attendance or academic engagement (Melvin et al., 2019). At the exosystem, Melvin and colleagues (2019) proposed that factors related to non-attendance include the availability of community support services, transport, and school factors such as school type, school climate and organisational factors. At the macro-level, government policy on attendance, cultural values,

neighbourhood characteristics (especially poverty and household size) were identified as factors related to school non-attendance (Melvin et al., 2019).

Viewing the phenomenon of school non-attendance in ASD through the framework proposed by Melvin et al (2019) highlights the currently limited information on correlates of non-attendance in ASD. Kurita (1991) found that the presence of ID or lower intellectual skills were associated with a lower frequency of school refusal, but there was no association with demographic characteristics, medical history, or maternal neuroticism. Munkhaugen et al. (2017) examined associations between school refusal behaviour and living in an urban area, renting, low maternal education, living with one parent, illness in other family members, attending a secondary school, and having additional diagnoses. Of those factors, only illness in other family members was significantly associated with school refusal behaviour. Further analysis of the same sample revealed no association with child age, gender, total IQ score, comorbid conditions, or severity of autism symptoms, but children with school refusal behaviour were more likely to have difficulties with executive functioning, emotional and behaviour problems (Munkhaugen et al., 2019).

The aim of the present study was to provide a more comprehensive description of the school non-attendance of children with ASD. Drawing on data from an online survey of children with ASD (with and without ID) in the UK, we aimed to describe non-attendance at the broader level of school absence, and investigate a wide range of potential correlates of non-attendance across different levels of influence (cf. Melvin et al., 2019). In addition, for the first time we used a systematic typology to describe the types of non-attendance in children with ASD (Heyne et al., 2019). In the absence of previous research, and given the descriptive nature of the study, we had no specific hypotheses about the direction of study findings.

### Method

# **Participants**

Caregivers were invited to participate in an online survey if they had a child with ASD and the child was enrolled at school (or preschool). A total of 499 caregivers participated. After excluding participants whose children did not appear to meet inclusion criteria, the final sample comprised 486 participants (see Table 1). Children with ASD were on average 11 years-old (M=10.71, SD=3.38, Range 2.75 to 18.17 years), and most of them were male (69%). Overall, 21% (N=102) were reported to also have intellectual disability (ID), but additional conditions and physical health problems were rare as can be seen in Table 1. The majority (75%) lived at home with both parents, and in all households the language spoken was English (96%) or English with another language (4%). Responding caregivers were mostly parents: 461 mothers (95.6%), 13 fathers (2.7%), while those remaining were grandparents or other caregivers. About half of the caregivers were educated to university degree level or above (50%) and were in paid employment (57%).

# Measures

School non-attendance. Parents were provided with a list of all school days in March 2017 and asked to indicate any day their child had been absent from school that day (possible maximum was 23). This provided a measure of absence on any given day (school day missed or not), a total count of days missed during March 2017 (range 0 to 23 days), as well as a binary indicator of persistent school absence defined using the 10% threshold (3 days or more) specified by the UK Department for Education (DfE, 2019b).

*Type of school non-attendance*. The School Non-Attendance ChecKlist (SNACK; Heyne et al., 2019) is a scale designed to permit a systematic typology for school non-attendance. For each day missed, the parent selects one reason from a list of 14 reasons provided (and a 15<sup>th</sup>

reason classed as Other). These reasons are classified into 5 types: non-problematic absenteeism (SNACK reasons 1,2,8,9,10,11 and 14), school refusal (SNACK reason 3), truancy (SNACK reason 4), school withdrawal (SNACK reasons 5,6,7), and school exclusion (SNACK reasons 12,13). SNACK items are accompanied by examples to make it easier for the parent to identify the most relevant reason for absence. As an example, SNACK reason 3 indicates: 'My child was reluctant or refused' for example: 'he/she said it was hard to go to school or to stay there the whole day'; 'he/she seemed upset/anxious/scared about school'.

When selecting SNACK reason 15 (other), parents were invited to provide a written description of the reason for absence. Two researchers (VT and RH) analysed the parent scripts to explore whether some of these reasons could be recoded into one of the other SNACK reasons, and to identify the most frequently cited reasons for 'other reason for absence'. Decisions were guided by a coding protocol our research team has developed using data across UK and Australia, and researchers jointly agreed on any recoding (protocol available on request by the first author).

Demographic characteristics of the child, family, school. Information was collected about the child with ASD (age, gender, associated ID [respondent reported only], physical health problems), the caregiver (their relationship with the child, educational qualifications, employment status) and the family (number of children at home, additional children with disabilities, language spoken at home, living arrangements for the child with ASD). We collected data on the type of school the child attends, whether the child had moved school, and how the child gets to school in the morning (method of transportation). These data were recoded for the purpose of analysis. Child gender was recoded to identify boys, as compared to girls and children of other gender. The child's living arrangement was recoded to identify children living in a two-parent household, compared to children living with a sole parent, or other relative or in residential care. The parent's employment status was recoded to identify

parents who were in paid employment (full-time, or part-time, or employed but currently in long-term leave) compared to parents who were not in employment (and either looking for work or not looking for work). Parental educational qualifications were recoded to identify parents with a University degree or higher qualification, compared to parents with no qualifications or qualifications lower than a University degree.

The type of school attended was recoded into mainstream versus other type. Under mainstream, children attended a mainstream classroom in a mainstream school or a special unit/classroom attached to a mainstream school. Other types of schools included special school day time, special residential school, pupil referral units, and other types (e.g., Vulnerable Learners' Centre, online school). School move was a variable created to indicate whether the student had attended more than one school, excluding the natural transition between primary and secondary. Last, data on how the child goes to school were recoded to indicate whether the child travelled independently (walk, ride bike/scooter, public transport) or not (family car, carpool, taxi and school bus).

## Procedure

The study was approved by independent reviewers across the Faculty of Social Sciences at the University of Warwick, UK. The month of March was selected as appropriate for the purposes of the study as during 2017 there were no school holidays scheduled during that month. The survey was launched on 3<sup>rd</sup> April 2017, the first working day following the end of the month for which we wanted to collect school attendance data, to ensure the information could be remembered easily by caregivers. The survey was active for 6 weeks only, to ensure that data collection was not too temporally distanced from the phenomenon under study. The survey was advertised through social media (Twitter, Facebook) and mailing lists by the autism organisation supporting this study (Ambitious About Autism). The recruitment

material focused on school attendance (as opposed to non-attendance), and parents were invited to indicate attendance for every day of the month, not just the days missed.

Participation in the survey was completely anonymous, and participants provided written consent for their participation.

Approach to statistical analysis

Descriptive statistics were used to describe the level of non-attendance. Non-attendance was defined in three ways: (a) missing school on any one of the given days (day absence), (b) the total number of school days missed (0 to 23 range), and (c) the percentage of persistent absence (defined as missing over 10% of available sessions; DfE, 2019b).

We explored potential correlates of school non-attendance in multi-variable regression models that included a series of child, family/caregiver characteristics, as well as school type and school access as predictors. The aim of these models was to generate an adjusted estimate of the association between non-attendance and child, family, or school factors. The type of regression model differed depending on the nature and distribution of the outcome variable. The total number of days missed was modelled using a Generalised Linear Model [GLM] with negative binomial link. Persistent absence was initially modelled using log-binomial GLM but, as this model did not converge, a Poisson GLM with log link was fitted (Knol, Le Cessie, Agra, Vanderbroucke, & Groenwold, 2012). Finally, day absence data were fitted in a Generalized Estimating Equation (GEE), which is the equivalent of GLM for repeated measurements. This last model included a further variable (whether the day missed was close to the weekend) in addition to all other predictors included. Exponential estimates derived from these models are interpreted as Relative Risks (RR) (Knol et al., 2012).

Descriptive statistics described types of non-attendance, as identified by the SNACK (Heyne et al., 2019). We estimated the rate of absence for each type over the total number of days missed. Among children with at least one day absent, a Poisson GLM with log link examined potential correlates of school withdrawal. GLMs with negative binomial log link (to account for overdispersion) examined the association between child, family and school factors with non-problematic absenteeism, school exclusion and school refusal.

## Results

Overall levels of school non-attendance

Figure 1 presents the number of school days missed during the data collection period. Of the 23 school days in March 2017, participants missed on average 5 days (M= 4.65, SD= 6.70, range 0 to 23). The median number of days missed was 2. Overall, 64% (N=313) missed one day or more. Seven percent of students (N=36) did not attend school on any of the 23 days. Persistent absence was reported for 43% of children in the current study (N= 211).

-----Insert Figure 1 here-----

Factors associated with school non-attendance

To examine the association between child, family, and school characteristics with school non-attendance, we fitted three multi-variable models for each of the three non-attendance outcomes: (1) total number of days missed over the study period (range 0 to 23), (2) persistent absence (child missed 10% or over of the available sessions) and (3) absence on any given day (day absence). Table 2 presents the adjusted RRs from these models along with 95% Confidence Intervals (CI). Upper and lower CIs that do not cross one indicate a statistically significant RR (highlighted in bold font in Table 2). It is important to keep in mind that the design is cross-sectional, and that RR do not confer information on the magnitude of risk, but indicate the magnitude of the association (i.e., the effect size). It is also

important to note these effects sizes (RRs) are adjusted, as the multivariable models have accounted for the effect of the other potential covariates.

Interestingly, the same four variables were consistently associated with any non-attendance outcome: attending a mainstream school, not living in a two-parent household, parental unemployment, and child age all increased the risk of school non-attendance. In particular, attending a mainstream school had the largest adjusted RR (ranging from 1.79 to 2.04) suggesting the risk of non-attendance increased by 104% for persistent non-attendance, by 100% for total days absent, and by 79% for total number of days missed. As the age of the child increased, the risk of not attending school increased by 7 - 8% across non-attendance outcomes (RRs ranging from 1.07 to 1.08). Not living in a two-parent household increased the risk of non-attendance by 37- 75% (RRs ranged from 1.37 for persistent absence to 1.75 for absence on any given day). Similar associations were seen for parental unemployment. When the parent reported not being in paid employment, the risk of non-attendance increased by 52 - 78%: the risk increased by 52% for persistent absence, 57% for total days missed, and 78% for day absence (RRs ranged from 1.52 to 1.78).



Types of school non-attendance

SNACK data provided by the parents are summarised in Table 3. Table 3 presents data for each reason separately but also the summary typology proposed by SNACK that classifies non-attendance into non-problematic absenteeism (NPA), school refusal, school exclusion, truancy, and school withdrawal. Forty-three per cent of days missed were missed because of school refusal, and this was the most frequent reason. More specifically, school refusal was mentioned as the reason for missing at least one day of school for 171 children (35%). For 19% of study participants school refusal was the reason that accounted for all days missed.

The second most frequent reason for missing school was NPA (32%). Within NPA, having a medical appointment or illness accounted for 13% and 18% of days missed, respectively. School exclusion and school withdrawal each accounted for 9% of days missed. School withdrawal was selected as a reason for 42 children (see first column Table 3, withdrawal was the reason provided for missing at least one day for 42 children). School exclusion was the reason indicated for missing at least one school day for 26 children.

-----Insert Table 3 about here-----

Table 4 presents the reasons provided in relation to persistent absence. For children with non-persistent absence, 47% of days were missed because of NPA, and 31% of days were missed because of school refusal. Among children with persistent absence, school refusal was the most frequent reason, accounting for almost half of days missed (49%), whereas NPA accounted for a quarter of missed days (25%).

-----Insert Table 4 about here -----

Taken together, parents indicated that school refusal was the most frequent reason for missing school, accounting for 43% of days missed. Almost half (49%) of the school days missed by children with persistent absence were missed because of school refusal.

Conversely, about half of the school days missed (47%) by children with low levels of absence were missed due to NPA, mostly to attend a medical appointment or because the young person was unwell.

Factors associated with types of non-attendance.

We examined potential correlates of NPA, exclusion, refusal, and withdrawal. Truancy was not examined because it was very rare in the sample. GLM models included all the covariates also used in the non-attendance models (see Table 2) but here the sample was restricted to the 313 children who missed 1+ days of school. Among children who missed any school days,

refusal was more likely in older children (RR: 1.12, 95% CI: 1.05, 1.19, p<.001), whereas no other covariates were associated with refusal. School withdrawal was not associated with any of the variables considered. NPA was less likely when the child had moved schools (RR= 0.65, 95% CI: 0.45, 0.94, p=.02), but more likely when the child had an associated ID (RR= 1.64, 95% CI: 1.11, 2.40, p=.01).

School exclusion was marginally more likely in mainstream schools (RR: 2.76, 95% CI: 1.01, 7.55, p=.05), more likely when the child did not live in a two-parent household (RR: 2.55; 95% CI: 1.25, 5.21, p=.01), but less likely when parental educational qualifications were low (RR= 0.45, 95% CI: 0.22, 0.96, p=.03). The last RR was in a direction opposite than would have been expected on the basis of the previous statistical models on school non-attendance. This suggested a likely interaction might be present. We explored this possibility by fitting a 3-way interaction term between parental employment status, educational qualifications, and not living in a two-parent household. GLM results suggested there was a significant interaction (Wald chi-square = 26.02, p<.001): children who missed the most days because of exclusion (adjusted marginal mean of days: 3.90, SE: 2.58) were those who did not live in a two-parent household, where the parent was unemployed and where the parent also had high educational qualifications. After accounting for this interaction, attending a mainstream school was no longer associated with a significant RR (RR: 2.70, 95 CI: 0.99, 7.40, p=.053).

## Discussion

To our knowledge, this is the largest and most comprehensive investigation of school non-attendance in children with ASD. Prior studies had a narrower focus on school refusal (Kurita, 1991) or school refusal behaviour (Munkhaugen et al., 2017, 2019) whereas we investigated overall non-attendance and types of non-attendance (non-problematic

absenteeism, school refusal, truancy, school withdrawal, and school exclusion) using a new measure called the SNACK (Heyne et al., 2019). We used an inclusive framework (Melvin et al., 2019) to examine factors associated with non-attendance and made a first attempt to explore correlates of non-attendance types among students with ASD.

On average, students with ASD missed five school days over a school month (23 days in March 2017). Over 60% of students missed at least one day. Persistent absence, defined as at least 10% absence, was highly prevalent (43% of participants). To contextualise this, persistent absence in the same academic year (2016-2017) across all students in England was 10.8%, and 17.3% for students with ASD (DfE, 2018). The level of persistent absence in our study was significantly higher than both national figures for England (p<.001). Differences between the English national data and our data might be attributed to our sampling design and the way ASD is defined in each case. In relation to sampling design, our study recruited across the UK, not just England, and was based on convenience sampling. Parents with more experiences of school non-attendance may have been more likely to respond to the survey, despite an advertisement focus on school attendance, rather than non-attendance. In terms of ASD definition, the English national data on ASD include just those students with ASD as the primary need in an Education, Health and Care Plan (EHCP) or a Statement of Special Educational Needs (SSEN). An EHCP, and its predecessor the SSEN, are effectively the formal means of identification of any need in the English educational system. One need is designated as primary in the EHCP or SSEN, and in this case this would be ASD. Any national data on ASD would identify just this group of students. However, not every student with ASD may also have an EHCP (or SSEN); their additional educational needs may be addressed through a lover level of support which is known as School Support. Our study included students with ASD regardless of whether they also had EHCP or SSEN. So we may have included students with ASD without EHCP whose attendance is not recorded in the

national ASD data. Further, we included students with additional developmental disabilities (e.g., ID) whose persistent attendance rates might be captured under different groupings in national figures. For example, persistent absence for children with ID as the primary need is much higher in national data, ranging between 18.5% to 44.6% depending on ID severity.

Informed by Melvin et al.'s (2019) framework, we collected data on child, parent, family, and school characteristics. Whichever way non-attendance was defined (absent on any one day, total days absent, and persistent absence), the same four factors were associated with higher levels of non-attendance: attending a mainstream school, being older, not living in a two-parent household, and parental unemployment. Evidence from populations without ASD supports findings of associations with older child age (Skedgell & Kearney, 2018), single parent households (Ferrell, 2009), and parental unemployment (Thornton, Darmody, & McCoy, 2013). Gottfried and colleagues (2017) reported that students with disabilities in mainstream schools were less likely to be absent from school. The direction of this effect is in the opposite direction to present findings, but in Gottfried et al. (2017) children attended primary schools, and data from students with ASD were not examined separately. Among students with disabilities, persistent non-attendance may be higher in secondary education compared to primary (US Department of Education, 2016). The profile of students who attend mainstream schools may differ from the profile of students who attend special schools, and these differences may also in part account for the association between non-attendance and type of school seen in the present study. More studies are needed to examine the association between non-attendance and type of school to confirm whether attending mainstream school increases the risk of non-attendance among students with ASD. Qualitative evidence suggests that students with ASD experience mainstream school settings negatively (Goodall, 2018).

We found no associations with low parental education which has been linked to non-attendance in the general student population (Balkis, Arslan, & Duru, 2016). Furthermore, there were no associations with independent transport to school, which might provide more opportunities for non-attendance.

Importantly, the present study indicated that reasons for non-attendance were varied. School refusal was the most frequent reason for non-attendance, with 43% of all absences due to refusal. This is comparable to Munkhaugen and colleagues' (2017) finding of teacher-reported 'school refusal behaviour' in children with ASD without ID (42.6%) but lower than parent-reported 'school refusal behaviour' in the same sample (53.2%). It should be kept in mind that this Norwegian study defined 'school refusal behaviour' more broadly than Heyne and colleagues' (2019) conceptualization of school refusal in the SNACK. In the current sample, non-attendance due to school refusal was higher than reported in an earlier Japanese study (27.3%; Kurita, 1991) of students with ASD and/or ID, and defined school refusal in a similar way to the definition used here. This difference might be related to the fact that Kurita's sampling design was based on recruitment from clinical diagnostic services, not the community as in our study, and any changes in the conceptualisation and identification of ASD over time.

School refusal was only associated with older child age, out of all possible correlates explored. Previous studies identified very few correlates of refusal, most notably emotional and behaviour problems (associated with SRB; Munkhaungen et al., 2019). Depression and anxiety may precipitate school refusal or SRB (Kearney, 2008). Future studies are required to examine a wider range of potential correlates of school refusal, including anxiety and depression that are highly prevalent in ASD (Simonoff et al., 2008).

The second most frequent type of absence was NPA, which accounted for 32% of all missed days. NPA mostly included absences due to illness and medical appointments. The high rate of NPA could be related to the increased likelihood of complex multi-morbidities in developmental disabilities (Doshi-Velez, Ge, & Kohane, 2014). Our finding of an association between NPA and ID supports the above hypothesis, and highlights that children with ASD and ID are at higher risk of non-attendance for health reasons, especially non-persistent absence. The notion that NPA is not problematic for the child's education and well-being is debatable particularly when it is persistent, thus justifying further study (Tonge & Silverman, 2019).

Truancy was almost non-existent, as it accounted for less than 1% of absences, even though its prevalence in the general student body is likely higher (between 4% and 6%; Egger, Costello, & Angold, 2003; Hancock, Gottfried, & Zubrick, 2018). The very low prevalence in our study may relate to the fact that the data source was the parent who may not know the true extent of a child's truancy (Gentle-Genitty, Karikari, Chen, Wilka, & Kim, 2015; Heyne et al., 2019). Future studies on truancy need to include data from self-reporting students with ASD, or from teachers.

School exclusion accounted for 9% of missed days. Studies into the experience of exclusion in ASD have identified significant difficulties for students with ASD that arise because of the way school environments are set up (e.g., linked to sensory difficulties for students, lack of predictability), difficulty relating to teachers and peers (including bullying experiences), teachers' lack of understanding of the needs of a child with ASD, and unsuccessful attempts to deal with students' behaviour (Brede et al., 2017; Sproston, Sedgewick, & Crane, 2017). In the overall student population, the association between poverty and exclusion is well established (e.g., Lereya & Daighton, 2019), but our data provide a more nuanced picture of socio-economic correlates of school exclusion. We found

a higher risk of school exclusion among single-parent, unemployed, and well-educated parents. This pattern of findings may reflect parent capacity to become involved with school exclusion processes (ie., more time or more educational resources) or teacher perceived parent capacity to do so (Gazeley, 2012; Kultz, 2015). Qualitative evidence on exclusion experiences from staff indicates attributions of parent-behaviour that are classed (see p.305; Gazeley, 2012) suggesting parents with more knowledge of the education system are more likely to confront the school about the child's needs. Future research should seek to replicate the association between exclusion and interacting parent socioeconomic characteristics, as this will help determine whether the current findings were a statistical fluke or a pattern in this population.

Finally, school withdrawal accounted for 9% of absences. Overall, parent-initiated withdrawal of a child from school is a phenomenon that is less well-researched than other types of non-attendance. In our study school withdrawal was not associated with any parent, child, family, or school factors we investigated, suggesting that other factors need to be explored. As a phenomenon, school withdrawal may be more frequent than present findings suggest because it could include children being permanently withdrawn from school, in some cases to be home-schooled (i.e., groups not included in our study). Parents of children with ASD often report that they withdraw their children from school to home-school them because they feel the school cannot adequately meet their child's needs (Kendall & Taylor, 2016).

In addition to the design limitations mentioned in the paragraphs above, further limitations relate to the lack of data on the presence of developmental conditions - other than ID - (e.g., ADHD, specific learning disabilities) which may further impact on school attendance patterns. In the interest of brevity, our survey did not investigate several factors that may also be associated with non-attendance (child emotional and behaviour problems, parental mental health, or factors in other levels of the bio-ecological framework), and, in

particular, did not describe the severity of autism symptoms, the extent of communication or social interaction difficulties, or the spectrum of adaptive skills. Future studies need to include such measures as they may help us identify sub-groups of students with ASD who may be at higher levels of risk for non-attendance. The (temporal) closeness of the survey to the period investigated may lend some confidence that parents reported correctly patterns and reasons for attendance, but does not preclude the possibility of memory errors. Future research could explore whether a daily diary method could provide more accurate data.

Finally, 7% of students in our study were reported to have missed the entire month (all 23 days). A post-hoc exploration of their profile indicated that these students were not different to the remaining students in terms of any of the demographic characteristics we measured. However, students presenting with refusal or exclusion included those who missed the entire month (Table 3). Three students missed all 23 days because of school exclusion and 21 because of school refusal. While our findings do not suggest this group of students was different from other students, future longitudinal research should explore the trajectory of students with prolonged non-attendance as it may be a particularly vulnerable group in terms of educational experiences and outcomes.

## Conclusion

The present study suggests that school non-attendance is common among students with ASD, and levels of persistent non-attendance are concerning. Older students from mainstream schools living in households with single or unemployed parents are more likely to miss school. Approximately 4 in 10 missed days were due to school refusal. Findings highlight that supporting students in mainstream schools with high levels of persistent absence is a priority, especially students with school refusal but also those with NPA. Multi-component support models that incorporate psychological support in school have shown promise with

adolescents with ASD (e.g., Brouwer-Borghuis, Heyne, Sauter, & Scholte, 2019) and need to be further tested. School withdrawal and school exclusion were less prevalent, but at 9% their levels are worrying as they are significant societal problems with far-reaching consequences for the students and their families. Stakeholders are concerned about increases in undocumented home-schooling and exclusion of children with ASD (SENPRF, 2019). Solutions are beginning to be explored (e.g., Obsuth et al., 2016 conducted a large-scale trial trying to improve rates of school exclusion in schools in the UK) but we need to accelerate the rate of testing potential solutions through rigorous designs, such as randomised trials. Importantly, we need to tailor proposed interventions to our current knowledge about non-attendance drivers in ASD.

## References

- Able, H., Sreckovic, M. A., Schultz, T. R., Garwood, J. D., & Sherman, J. (2015). Views from the trenches: Teacher and student supports needed for full inclusion of students with ASD. *Teacher Education and Special Education*, 38, 44–57.
- Balkis, M., Arslan, G., & Duru, E. (2016). The school absenteeism among high school students: Contributing factors. *Educational Sciences: Theory & Practice*, 16, 1819-1831.
- Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. (2017). Excluded from school: Autistic students' experiences of school exclusion and subsequent reintegration into school. *Autism and Developmental Language Impairments*, 2, 1-20.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In W. Damon & R.M. Lerner (Eds.), *Handbook of Child Psychology, Theoretical Models of Human Development, Vol. 1* (pp 793-828). Hoboken, NJ: Wiley.Brouwer-Borghuis, M., Heyne, D., Sauter, F., & Scholte, R. (2019). The Link: An alternative educational program in the Netherlands to re-engage school-refusing adolescents in mainstream schooling. *Cognitive and Behavioral Practice*, 26, 75-91.
- Department for Education (2018). *Pupil Absence in Schools in England: 2016 to 2017*. 22

  March 2018 National Statistics. London: Department for Education. Retrieved July 2019 from <a href="https://www.gov.uk/government/statistics/pupil-absence-in-schools-in-england-2016-to-2017">https://www.gov.uk/government/statistics/pupil-absence-in-schools-in-england-2016-to-2017</a>
- Department for Education (2019a). *Pupil Absence in Schools in England: 2017 to 2018*. 21

  March 2019 National Statistics. London: Department for Education. Retrieved July 2019 from <a href="https://www.gov.uk/government/statistics/pupil-absence-in-schools-in-england-2017-to-2018">https://www.gov.uk/government/statistics/pupil-absence-in-schools-in-england-2017-to-2018</a>

- Department for Education (2019b). *A Guide to Absence Statistics*. London: Department for Education. Retrieved July 2019 from <a href="https://www.gov.uk/government/publications/absence-statistics-guide">https://www.gov.uk/government/publications/absence-statistics-guide</a>
- Doshi-Velez, F., Ge, Y., & Kohene, I. (2014). Comorbidity clusters in autism spectrum disorders: an electronic health record time-series analysis. *Pediatrics*, 133, e54-63.
- Epstein, S., Roberts, E., Sedwick, R., Polling, C., Finning, K., Ford, T., Dutta, R., & Downs, J. (in press). School absenteeism as a risk factor for self-harm and suicidal ideation in children and adolescents: a systematic review and meta-analysis. *European Child and Adolescent Psychiatry*. <a href="https://doi.org/10.1007/s00787-019-01327-3">https://doi.org/10.1007/s00787-019-01327-3</a>
- Egger, H. L., Costello, J. E., & Angold, A. (2003). School refusal and psychiatric disorders:

  A community study. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42, 797-807.
- Ferrell, R.T. (2009). The effects of single-parent households versus two parent-households on student academic success, attendance and suspensions. Doctorate of Education, Lindenwood University.
- Gazeley, L. (2012). The impact of social class on parent–professional interaction in school exclusion processes: deficit or disadvantage? *International Journal of Inclusive Education*, 16, 297-311.
- Gentle-Genitty, C., Karikari, I., Chen, H., Wilka, E., & Kim, J. (2015). Truancy: A look at definitions in the USA and other territories. *Educational Studies*, 41, 62-90.
- Goodall, C. (2018). 'I felt closed in and like I couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people. *Autism and Developmental Language Impairments*, 3, 1-16.

- Gottfried, M., Stiefel, L., Schwartz, A. E., & Hopkins, B. (2017). Showing Up: Disparities in Chronic Absenteeism between Students with and without Disabilities. IESP Working Paper #03-17. New York: Institute for Education and Social Policy
- Heyne, D., Gren Landell, M., Melvin, G., & Gentle-Genitty, C. (2019). Differentiation between school attendance problems: Why and how? *Cognitive and Behavioral Practice*, 26, 8-34.
- Heyne, D., King, N.J., Tonge, B.J., & Cooper, H. (2001). School refusal: Epidemiology and management. *Pediatric Drugs*, 3, 719-732.
- Hancock, K. J., Shepherd, C. C., Lawrence, D., & Zubrick, S. R. (2013). Student attendance and educational outcomes: Every day counts. *Report for the Department of Education, Employment and Workplace Relations, Canberra*.
- Hancock, K. J., Gottfried, M. A., & Zubrick, S. R. (2018). Does the reason matter? How student-reported reasons for school absence contribute to differences in achievement outcomes among 14–15 year olds outcomes among 14–15 year olds. *British Educational Research Journal*, 44, 141-174.
- Kearney, C. A. (2008). School absenteeism and school refusal behavior in youth: A contemporary review. *Clinical Psychology Review*, 28, 451-471.
- Kendall, L., & Taylor, E. (2016). 'We can't make him fit into the system': parental reflections on the reasons why home education is the only option for their child who has special educational needs. *Education 3-13*, 44, 297-310.
- Knol, M.J., Le Cessie, S., Algra, A., Vandenbroucke, J.P. & Groenwold, R.H.H. (2012).Overestimation of risk ratios by odds ratios in trials and cohort studies: alternatives to logistic regression. *Canadian Medical Association Journal*, 184, 895-899.
- Kurita, H. (1991). School refusal in pervasive developmental disorders. *Journal of Autism* and *Developmental Disorders*, 21, 1-15.

- Kulz, C. (2015). Mapping the exclusion process: Inequality, justice and the business of education. London: Communities Empowerment Network. Retrieved November 2019 from <a href="http://conflictmatters.eu/conference-2017/wp-">http://conflictmatters.eu/conference-2017/wp-</a> content/uploads/2017/10/Mapping-the-Exclusion-Process.pdf
- Lereya, T., & Deighton, J. (2019). Learning from HeadStart: the relationship between mental health and school attainment, attendance and exclusions in young people aged 11 to 14. London: EBPU. Retrieved July 2019 from <a href="https://www.ucl.ac.uk/evidence-based-practice-unit/headstart-learning-team/headstart-reports-publications">https://www.ucl.ac.uk/evidence-based-practice-unit/headstart-learning-team/headstart-reports-publications</a>
- Lleras-Muney. A. (2005). The relationship between education and adult mortality in the United States. *Review of Economic Studies*, 72, 189-221.
- Melvin, G., Heyne, D., Gray, K.M., Hastings, R.P., Totsika, V., Tonge, B., & Freeman, M.
  (2019). The Kids and Teens at School Framework: The application of an inclusive nested framework to understand school absenteeism and school attendance problems.
  Frontiers in Education. 4. doi: 10.3389/feduc.2019.00061
- Munkhaugen, E.K., Gjevik, E., Pripp, A.H., Sponheim, E., & Diseth, T.H. (2017). School refusal behavior: Are children and adolescents with autism spectrum disorders at a higher risk? *Research in Autism Spectrum Disorders*, 41-42, 31-28.
- Munkhaugen, E.K., Torske, T., Gjevik, E., Nærland, T., Pripp, A.H., & Diseth, T. H. (2019). Individual characteristics of students with autism spectrum disorder and school refusal behavior. *Autism*, 23, 413-423.
- Obsuth, I., Sutherland, A., Cope, A., Pilbeam, L., Murray, A.L., & Eisner, M. (2017). London education and inclusion project (LEIP): Results from a cluster-randomized controlled trial of an intervention to reduce school exclusion and anti-social behavior. *Journal of Youth and Adolescence*, 46, 538-577.

- Schoeneberger, J. A. (2012). Longitudinal attendance patterns: Developing high school dropouts. The Clearing House: *A Journal of Educational Strategies, Issues and Ideas*, 85, 7-14.
- Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2007).

  Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academic of Child and Adolescent Psychiatry*, 47, 921-929.
- SEN Policy Research Forum (2019). Exclusions, barriers to admission and quality of
  mainstream provision for children and young people with SEND: what can be done?

  SEN Policy Research Forum. Retrieved July 2019 from

  <a href="https://www.sendgateway.org.uk/organisations.nasen.html">https://www.sendgateway.org.uk/organisations.nasen.html</a>
- Skedgell, K., & Kearney, C. A. (2018). Predictors of school absenteeism severity at multiple levels: A classification and regression tree analysis. *Children and Youth Services*\*Review\*, 86, 236-245.
- Sproston, K., Sedgewick, F., & Crane, L. (2017). Autistic girls and school exclusion:

  Perspectives of students and their parents. *Autism and Developmental Language Impairments*, 2, 1-14.
- Thornton, M., Darmody, M., & McCoy, S. (2013). Persistent absenteeism among Irish primary school pupils. *Educational Review*, 65, 488-501.
- Tonge, B.J., & Silverman, W.K. (2019). Reflections on the field of school attendance problems: For the times they are a-changing. *Cognitive and Behavioral Practice*, 26, 119-126.

Townsend, L., Fisher, A.J, & King, G. (2007). A systematic review of the relationship between high school dropout and substance use. *Clinical Child and Family Psychology*, 10, 295-317.

United States Department of Education (2016). *Data visualizations of chronic absenteeism in our nation's schools*. Retrieved July 2019, from

https://www2.ed.gov/datastory/chronicabsenteeism.html

Table 1. Profile of students with autism spectrum disorders

		N (%)
	Total participants	486 (100)
Child gender	Child with ASD is a boy	334 (69)
Child age	Child is 12 years old or older	182 (41)
Co-occurring conditions	Intellectual Disability	102 (21)
	Cerebral Palsy	2 (0.4)
	Down Syndrome	2 (0.4)
	Fragile X syndrome	1 (0.2)
	Prader Willi Syndrome	1 (0.2)
	Spina Bifida	1 (0.2)
	Tuberous Sclerosis Complex	1 (0.2)
	Acquired Brain Injury	4 (0.8)
Physical health	Sensory Impairment (vision, hearing)	6 (1.2)
	Epilepsy	15 (3.1)
	Mobility issues (hemiplegia, paraplegia,	2 (0.4)
	quadriplegia, cerebral palsy)	
Living arrangements	Child lives at home with both parents	361 (75)
Child school	Child attends mainstream school	392 (81)
School transport	Child goes to school by family car	238 (50)
Caregiver characteristics	Caregiver educated at University degree	222 (46)
	level or above	
	Caregiver has disability/illness	169 (35)
	Caregiver is in paid employment	275 (57)

Table 2

Potential covariates of total count of school days missed, persistent absence, and school absence on any given day (absent/not absent).

	Total number of days missed	Persistent absence (10%+)	Day absence
	RR <sup>1</sup> (95% CI)	RR <sup>1</sup> (95% CI)	RR <sup>2</sup> (95% CI)
Child is a boy	0.91 (0.68, 1.20)	0.88 (0.71, 1.09)	0.89 (0.62, 1.27)
Child has intellectual disability	1.08 (0.78, 1.50)	1.01 (0.77, 1.31)	1.11 (0.72, 1.71)
Centred child age	1.07 (1.02, 1.11)	1.07 (1.03, 1.10)	1.08 (1.03, 1.14)
Not a two-parent household	1.59 (1.18, 2.14)	1.37 (1.10, 1.70)	1.75 (1.16, 2.64)
Parent not in paid employment	1.57 (1.18, 2.10)	1.52 (1.22, 1.89)	1.78 (1.22, 2.60)
Low parental educational qualifications	0.83 (0.63, 1.11)	0.88 (0.71, 1.09)	0.79 (0.56, 1.12)
Family has more children with disabilities	1.08 (0.77, 1.51)	0.94 (0.75, 1.19)	1.07 (0.70, 1.63)
Total number of children in household	1.10 (0.97, 1.25)	1.07 (0.98, 1.17)	1.14 (0.97, 1.34)
Child attends a mainstream school	1.79 (1.20, 2.66)	2.04 (1.14, 3.62)	2.00 (1.20, 3.31)
Child goes to school independently	0.83 (0.61, 1.12)	0.90 (0.71, 1.13)	0.82 (0.56, 1.20)
Child has changed schools	1.32 (1.00, 1.74)	1.01 (0.82, 1.25)	1.30 (0.90, 1.89)
Day missed was close to weekend	n/a	n/a	1.00 (0.92, 1.09)

<sup>1</sup> Adjusted Relative Risk from Generalised Linear Model; <sup>2</sup>Adjusted Relative Risk from Generalised Estimating Equation. **Bold** indicates p<.05

 $\label{eq:able_3} \emph{Parent-reported reasons for non-attendance, and associated types of non-attendance}$ 

	N students <sup>1</sup>	Min-Max	% days missed	N of students who missed all
SNACK reason		days	because of	days because of
1-child had appointment	72	0-6	13	26
2-child was sick	89	0-11	18	28
3-child refused	171	0-23	43	94
4-child truanted	4	0-3	<1	1
5-parent gave child day off	26	0-9	5	8
6-parent kept child at home	9	0-8	2	3
7-parent arranged extra holidays	7	0-5	2	6
8-family urgency	5	0-3	1	2
9-family had other difficulties	3	0-1	<1	0
10-religious holiday	0	0	0	n/a
11- school closed	4	0-7	<1	0

12-school sent child home	26	0-10	4	7
13-school asked that child stay home	27	0-23	5	6
14-weather	0	0	0	n/a
15-other reason	23	0-23	5	9
Type of non-attendance				
Non-problematic absenteeism	148	0-11	32	67
School Refusal	171	0-23	43	94
Truancy	4	0-3	<1	1
School Withdrawal	42	0-9	9	17
School Exclusion	26	0-23	9	16

<sup>&</sup>lt;sup>1</sup> N of students for whom reason/type was recorded

Table 4

Type of school non-attendance in relation to persistent absence

	Students with persistent	Students with non-	
	absence	persistent absence	
	(%)	(%)	
Non-problematic absenteeism	25	47	
School refusal	49	31	
Truancy	<1	1	
School withdrawal	6	14	
School exclusion	11	6	

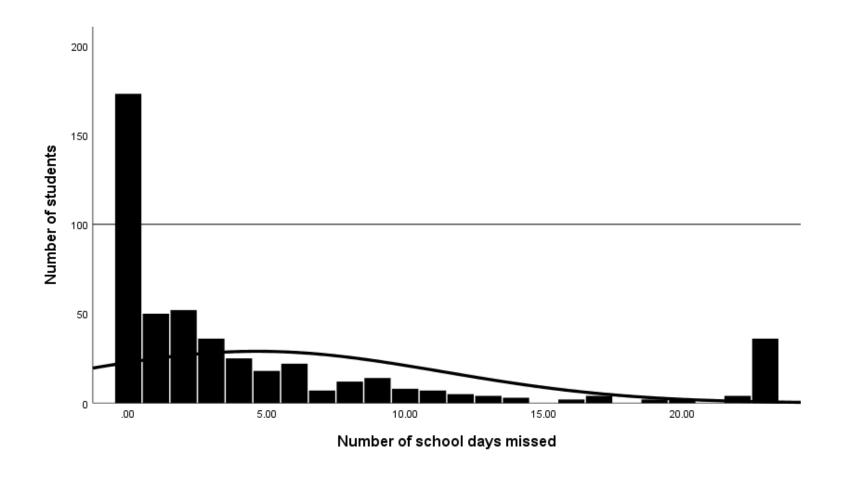


Figure 1. The distribution of the number of days students with ASD did not attend school during March 2017 (23 total school days).