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The Prevalence of Selective Mutism and Autism in Mainstream Government Funded Schools in England – A Pilot Study

S. A. Landrock-White[a]*, L. Lenton[a], J. V. J. Roe[a] and C. A. Rogers[b]

[a]*Selective Mutism Information and Research Association,* 5th Floor, *SMiRA, 167-169 Great Portland St, London W1W 5PF;* [b]*Bristol Medical School, University of Bristol, Bristol, England ORCHID 0000-0002-9624-2615*

*Dr. Shirley Landrock-White, shirley@selectivemutism.org.uk ORCHID 0000-0003-2668-0334; Linkedin https://www.linkedin.com/in/shirley-landrock-white-9bb820327/

Statements and Declarations

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Selective mutism (SM) is an anxiety disorder affecting the ability to speak which can co-occur with other conditions such as autism and social anxiety. This pilot study captures statistics on the number of students aged 12-15 in mainstream state funded schools in England with a diagnosis of autism, SM, both or neither. Of the 624 schools contacted data were provided from 14 schools with 8159 students (4397 male sex and 3762 female sex). One was a single-sex boys' school. The number of students per school ranged from 305 to 882 (median 572). In total 274/8159 (3.36%) students were autistic, 26/8159 (0.32%) had SM and 7/8159 (0.086%) were both autistic and had a diagnosis of SM. The prevalence of autism was higher amongst male than female students (rate per 100 students 4.6 versus 1.9) while the prevalence of SM was lower amongst male students (rate 0.16 versus 0.51 in females), and the rate of both conditions was similar (0.09 versus 0.08). Reasons for the under-reporting and under-diagnosis of SM in both males and females, and under-diagnosis of autism in females in relation to these findings are discussed. The importance of considering autism as possibly co-occurring with SM is also discussed.

Keywords: selective mutism; autism; comorbidity; school population

Introduction

Selective Mutism (SM) is an anxiety disorder in which people consistently fail to speak or are unable to speak freely in specific social situations, whilst being able to speak normally and with 'adequate language competence' in others (ICD-11 World Health Organization 2022). It is usually noticed first in early childhood but can perpetuate throughout life causing interference with educational attainment and social communication. Severity and range of symptoms, and the level of disability caused by

them, varies between individuals but can have serious long-term effects (Kamani and Monga 2020).

SM has a heterogenous presentation (Kearney and Rede 2021) and is often comorbid with other anxiety disorders such as Social Anxiety Disorder and Separation Anxiety Disorder and there is increasing evidence that there is a relationship between SM and autism in some cases (Muris and Ollendick 2021). Some symptoms associated with SM and autism can be similar (e.g. poor eye contact, lack of speech, anxiety, intolerance of minor changes to routine, hyper-sensitivities) and can lead to confusion during diagnosis with some children being diagnosed incorrectly or comorbid diagnoses being missed (Johnson and Wintgens 2016).

Differences in timing and frequency of diagnosis between males and females

Petrou, Parr and McConachie (2018) found that girls were diagnosed with autism on average one year later than males, and that under-diagnosis was common. SM is diagnosed more frequently in females than males (Ford et al. 1998; Roe 2011).

The wording used historically in both the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD) to describe SM have caused confusion as to whether it is possible to diagnose both autism and SM as coexisting. Updates within DSM-5 (APA 2013) have now made allowance for dual diagnosis, whilst in ICD-11 (World Health Organization 2022), autism is still listed as an exclusion, however, it also states that in autism, unlike SM, 'language and communication impairments are notable across environments and social situations' which suggests that dual diagnosis is possible.

Selective mutism and Autism in the English School Population

Collective studies suggest the prevalence rate of SM in school aged children to be in the range of 0.03% to 2%, (Driessen et al. 2020; Kearney and Rede 2021). There is currently no national reporting of SM within health or education statistics in the United Kingdom (UK), and a lack of awareness of SM exists both in UK schools and amongst health professionals. Douglas (2021), in an interview study (n=6) of parents' experience of living with a child with SM in the UK, found that 'over half of the parents reported that nursery and school staff, and even professionals, had demonstrated a lack of awareness and understanding of SM'. The UK Government Bercow report of 2008 on Speech Language and Communication Needs (SLCN) provision for children in England concluded that, 'Accessing the right service sometimes just does not happen. When it does, maintaining continuity of support is an uphill struggle. Professionals do their best but face pressures on their time and resources.' (UK Government 2008). The Bercow: Ten Years On report of 2018 concluded that little had changed in the intervening decade, with SLCN services for children still being inaccessible and inequitable in England, with 'unacceptable variation across the country' (ICAN & RCSLT 2018).

Currently there are no National Institute for Health and Care Excellence (NICE) guidelines in the UK for SM and no national care pathway. This means that there is a postcode lottery when it comes to getting a diagnosis or access to any support for children with SM and their families.

NICE guidelines for autism in children (NICE 2017) list SM as a possible differential diagnosis, but do not include it as a possible co-existing condition. This means that if these guidelines are followed SM may not be diagnosed if a diagnosis of autism is also present.

Problems also exist with the reporting of the numbers of children with a diagnosis of SM in the UK. SM is not a category in UK Government statistics for Special Educational Needs in English schools, so the decision on how to categorise a child with SM is left to the individual schools. Of the 12 categories available there are at least three under which SM could be placed. (UK Government 2023). It is therefore not possible to use UK Government statistics to determine how many children in English schools have SM or SM co-occurring with autism.

The number of children diagnosed with autism within the English state school population, in contrast, is reported under a specific category within UK government statistics and is given as 206,763 children and young people in England in the 2022/23 academic year (all state school types). In a school population of 9.1 million this equates to a percentage of 2.27% (UK Government 2023).

Aims of the study

Increasing evidence suggests that there are children in the UK who are both autistic and have SM who would benefit from dual diagnosis allowing treatment to be individualised (Landrock-White, S., et al., 2026). The aims of this study were to estimate the prevalence of SM in the mainstream state school population in England and investigate any sex differences. An additional aim was to conduct an initial investigation into the level of co-occurrence of SM and autism.

Method

Participants and procedures

Special Educational Needs and Disability Coordinators (SENDCOs) of mainstream Government funded schools across England were contacted by E-mail with details of the research during the 2022 to 2023 school year. Schools in both rural and city

locations were approached. Special schools and independent (privately funded) schools were excluded. The SENDCOs were asked to complete an online survey that requested anonymous data on the number of students in school years 8, 9 and 10 (aged 12-15 at the start of the academic year) with or without diagnoses of autism, SM or both autism and SM, with data reported separately for male and female students (biological sex). A training video on SM prepared by a Speech and Language Therapist who specialises in SM was offered to all schools that took part in the survey.

Continuous data are summarised using means and standard deviations (or median and interquartile range if skewed) and binary data are summarised as number and percentage. Rates are presented per 100 students and are compared between males and females using the incidence rate ratio, combined across schools using the Mantel-Haenszel method. Rate ratios (male:female) are reported with 95% confidence intervals. Analyses were carried out using Stata version 18.0 (StataCorp LLP, College Station, Tx).

Results

Participants

In total 624 schools were contacted and invited to take part in the study. Sixteen schools responded: 14 of 16 schools supplied data on the diagnostic status of their students (age range 12 – 15, n = 8,159) and were included in the analysis. Of these 14 schools 12 were non-selective mixed sex, 1 non-selective boys only and 1 selective mixed sex. Nine schools were situated within cities (population >175,000), three in towns (population 7,500 to 174,999) and two in village locations (population <7,500). Seven English regions were represented (2 North West, 2 Yorkshire & Humber, 1 East Midlands, 1 West Midlands, 2 London, 3 South East, 3 South West). The number of

students attending the schools is summarised in Table 1. All schools had at least one autistic student, with the number ranging from 6 to 37 students. There were 26 students with SM and seven students who were both autistic and had SM. Of these seven students two were awaiting assessments to confirm the diagnosis. For this analysis, they were included with those confirmed. Thirteen of the 14 schools had at least one student with SM and five schools had at least one student who was both autistic and had SM. Autism was more common amongst male students than female students (rate ratio 2.35, 95% confidence interval 1.79 to 3.09), whilst SM was more common in females (rate ratio 0.29, 95% confidence interval 0.11 to 0.74). The rate for both diagnoses together were similar for males and females (rate ratio 1.31, 95% confidence interval 0.29 to 5.92).

Table 1

Characteristics of responder schools and rates of Autism and SM in these schools

	Female students	**Male students**	**Total**
Number of schools	13	14	14
Students at the school			
Number of students in school - mean (SD)	289 (79.6)	314 (74.9)	583 (167)
Range	177 to 418	183 to 464	305 to 882
Total students across all schools	3762	4397	8159
Autistic Students			
Number of students in school – median (IQR)	5 (3 – 7)	13.5 (11 – 19)	19 (15 – 24)
Percentage of students in school – median (IQR)	1.93 (1.20 – 2.18)	3.98 (2.90- 6.25)	3.03 (2.36 – 4.92)
Incidence rate per 100 students across all schools	1.91	4.59	3.36
Total autistic students across all schools	72	202	274
Total autistic students across all schools with SM	3/72 (4.2%)	4/202 (2.0%)	7/274 (2.6%)
Students with SM			

Number of students in school – median (IQR)	1 (0 – 2)	0.5 (0 – 1)	1 (1 – 2)
Percentage of students in school – median (IQR)	0.33 (0 – 0.55)	0.11 (0 – 0.33)	0.27 (0.15 – 0.33)
Incidence rate per 100 students across all schools	0.51	0.16	0.32
Total students across all schools with SM	19	7	26
Total students with SM across all schools also autistic	3/19 (16%)	4/7 (57%)	7/26 (27%)
Students both autistic and with SM			
Number of students in school – median (IQR)	0 (0 – 0)	0 (0 – 0)	0 (0 – 1)
Percentage of students in school – median (IQR)	0 (0 – 0)	0 (0 – 0)	0 (0 – 0.14)
Incidence rate per 100 students across all schools	0.080	0.091	0.086
Total students across all schools	3	4	7

SM = selective mutism, SD = standard deviation, IQR = interquartile range

Discussion

Rate of Autism

A diagnosis of autism was found to be more prevalent across the 14 schools in males (4.59%) than females (1.91%). UK Government (2023) gives 2.27% as the prevalence rate for autism across all children in all year groups and all state school types (including special schools and pupil referral units) which is lower than the finding in this study of 3.36%. This discrepancy may be due to the small number of schools who responded to the survey. The schools were also self-selecting and may be biased towards schools where the SENDCOs have a greater awareness or interest in autism and/or SM. Roman-Urrestarazu et al. (2022) found 3.9 times the incidence of autism in males in English Schools than in females, whilst in this study it was found to be 2.35 times higher. They also reported an overall prevalence rate of 1.76% in English state schools and a ratio of males to females of 4.32:1. The student population for this study (Years 8-

10, age 12-15) was a subset of the state school population rather than the whole state school population (age 2–21) as used by Roman-Urrestaruzu et al. (2021). This may in part explain the higher incidence of autism found here as the increased challenges of starting secondary school at age 11 (year 7) may lead to undiagnosed conditions becoming more difficult to manage, leading to diagnosis only being sought after commencement at this level, particularly for autistic females.

Diagnosis of autism in females is becoming more common with increased awareness of the differences in presentation between females and males; however, it is likely that autism is still under-diagnosed in females. Estrin et al. (2021) identified a number of perceived barriers to the identification and diagnosis of females: the perception that autism applies predominantly to males by both parents and clinicians who may not consider autism as a possible diagnosis and therefore look for alternative conditions first; camouflaging/compensatory behaviours in females; parents having fewer or differing concerns about females; behaviours in autistic females which do not fit with the male presentation of autism, such as females having similar social skills to neurotypical males, and fewer repetitive behaviours than autistic males.

Rate of SM

In this study a diagnosis of SM was found to be more common in females (0.51%) than in males (0.16%), with a total rate of 0.32% in line with the findings of Ford et al. (1998) and Roe (2011). The percentages found were within the range of 0.03% to 2% found in children by other international studies (Bergman, Piacentini and McCracken 2002; Driessen et al. 2020; Kearney and Rede 2021). The numbers are small though, so any inferences are tentative, however they may still underestimate the true prevalence of SM. Awareness of SM is increasing, but it is likely that there is still under-diagnosis of SM in both males and females due to lack of awareness and understanding of SM in UK

schools and amongst health professionals, parents being unaware of which services to go to, parents struggling to access specialist support services (Douglas 2021), SLCN services for children being unequal and highly variable across England (ICAN & RCSLT 2018), and the lack of NICE Guidelines or a national care pathway for SM.

ICD-10 (World Health Organisation 1992) is, at the time of writing, the manual still used routinely in the UK by the National Health Service (NHS) in which SM is listed under Behavioural and Developmental Disorders rather than anxiety disorders, and where the main diagnostic criterion is 'a marked, emotionally determined selectivity in speaking, such that the child demonstrates his or her language competence in some situations but fails to speak in other (definable) situations.' This is potentially problematic as it does not take into account that anxiety levels can fluctuate in a person with SM and so allow limited speech on some occasions whilst none on others. Anxiety is affected by many factors such as past or anticipated future events, not necessarily just the situation a person is in at the time.

In ICD-11 SM is now placed within anxiety disorders and has an expanded section on additional clinical features which show the nuances of SM better, but it still gives the main diagnostic criterion as 'Consistent selectivity in speaking, such that a child demonstrates adequate language competence in specific social situations, typically at home, but consistently fails to speak in others, typically at school'. This may result in continued under-diagnosis of children with limited or fluctuating patterns of speech in some situations associated with changes in their anxiety levels.

Rate of co-occurring autism and SM

The percentage of dual diagnosis of autism and SM was very small at 0.080% for females, 0.091% males, and 0.086% overall. These data included two males with

suspected comorbidity that was to be confirmed, excluding these two students would reduce the comorbidity rate in males to 0.045%. Under-diagnosis of SM in both females and males (Adamson, R. et al., 2025; Douglas, C., 2021), and under-diagnosis of autism in females (Petrou, A.M. et al., 2018) are likely to have had an influence on these data, as are difficulties with getting a dual diagnosis (Keville, S. et al., 2024) with the subsequent possibility that the co-occurrence rate may be higher in reality.

The data for dual diagnosis are not exclusive of the data for the two separate diagnoses, so it is possible to report the percentage of those who are autistic who also have SM and vice versa. The percentage of those who are autistic who also have SM is much smaller than the percentage with SM who are also autistic. The percentages are also in line in terms of magnitude with Steffenburg et al. (2018) who found 63% of their SM study group to have co-occurring autism. Since both autism and SM in females are likely to be under-diagnosed, and SM under-diagnosed in males, the extent to which these are happening could influence these figures and inferences based on them, however, the finding that 27% of the total study group with SM were also autistic would suggest that the possibility of autism coexisting should be considered in children presenting with SM during diagnosis. The number of children with dual diagnosis is very small, so inferences must be viewed with caution. The percentage found here is, however, similar to the 24% of children with SM who were also autistic found by the authors in a separate larger study (Landrock-White, S. et al., 2026).

Limitations and recommendations for further study.

Recruitment of schools to the study proved very difficult despite follow-up telephone calls being made or repeat E-mails sent to encourage participation. Five schools were recruited through the SMiRA website or Facebook group, representing people already researching SM which may have introduced bias towards schools who already had

children with a diagnosis of SM, as may the offer of a training video on SM, potentially resulting in a higher rate of SM being recorded than in reality.

The data were obtained from a subset of children from three school years only. In future asking for whole school data would be preferable to increase population size and improve accuracy of the prevalence of diagnoses.

The original design of this study included a request for the SENDCos and teachers to undertake SM training, and then identify children who either already had a diagnosis of SM or they suspected may have SM. They were then asked to contact parents, and with their permission and that of the young person, the SENDCo would fill in the School Speech Questionnaire (SSQ), (Bergman et al., 2002), and the parents the Selective Mutism Questionnaire (SMQ) (Bergman et al, 2002) for the young people. This data would have helped confirm diagnoses and identify potential undiagnosed cases of SM. It was not intended that the questionnaires would replace formal diagnoses. No school, however, would sign up to this part of the study. For future studies, as is common in published studies, it would be advisable to use the SSQ, SMQ and a reliable autism diagnostic instrument to give greater validity to the results (bearing in mind that no one individual instrument can properly diagnose autism).

Conclusion

The findings of this study underline the importance that professionals are made aware of the possibility of co-occurrence of SM and autism to enable early and more accurate diagnoses, since early intervention for SM is important in eliciting the quickest possible recovery, preventing entrenchment or the development of additional mental health problems (Kamani and Monga 2020; Oerbeck et al. 2018). Multidisciplinary teams should be used in the assessment and interventions for children with SM due to the

possibility of co-occurrence with autism and other conditions since methods will need to be adapted to individual needs.

Under diagnosis of SM in males and females and of autism in females needs to be addressed, with NICE guidelines being developed for SM. The postcode lottery faced by children with SM in England to get a diagnosis and support should cease and be replaced with a national care pathway fit for purpose which can be adapted to local conditions.

There are official statistics for autism but not SM in school and health data in the UK, so SM as a condition is unrepresented in data. Reporting needs to be changed so the number of children in schools and within the health services with SM is recorded, so an appropriate level of resources can be allocated, as SM is more treatable in childhood particularly in the very young (Johnson and Wintgens 2016).

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