

PILOT SURVEY OF AUTISTIC SCHOOL STAFF WHO WORK OR HAVE WORKED IN AN EDUCATION ROLE IN SCHOOLS IN THE UK: INITIAL SUMMARY REPORT

Dr Rebecca Wood

SENIOR LECTURER IN SPECIAL EDUCATION University of East London

PILOT SURVEY OF AUTISTIC SCHOOL STAFF WHO WORK OR HAVE WORKED IN AN EDUCATION ROLE IN SCHOOLS IN THE UK

INITIAL SUMMARY REPORT

DR REBECCA WOOD

1. BACKGROUND

This project was developed in 2019, towards the end of my ESRC postdoctoral Fellowship at the Social, Genetic and Developmental Psychiatry Centre at King's College London.

There are four key principles which underpin this research project:

- a. The need for a greater understanding of how to facilitate the employment and professional development of autistic people (Hendricks 2010)
- b. The right of autistic people to develop their potential, and to be supported in so-doing (Convention on the Rights of Persons with Disabilities 2006)
- c. The ongoing difficulties of enabling autistic children and young people to receive a suitable education which enables them to flourish (Wood 2019)
- d. The potential benefits to all pupils, and autistic pupils in particular, of being taught by autistic school staff (Wood 2019)

2. INTRODUCTION

The survey was developed with the input of a committee of autistic professionals who work in schools. It was launched, via SurveyMonkey, in November 2019 and ran for approximately five weeks. It was disseminated on social media and via teacher/education and university networks known to me. Participants needed to be over the age of 18, to have worked or be currently working in an education role in schools in the UK, and to have a diagnosis of autism (either professional diagnosis or self-diagnosis), or to be seeking a diagnosis of autism. In total, 149 participants completed the survey. Most questions were optional, therefore not all participants provided answers to all questions. This is a relatively simple summary of the main findings which will be analysed in greater depth in the coming months. All data are completely anonymised.

3. CORE FACTS AND FIGURES

- a. The **age range of participants** was from 19 62 years. The median age of participants was 40 years.
- b. Diagnostic status: 93 (62.4%) of participants had a medical/professional diagnosis of autism; 36 (24.2%) were self-diagnosed; 20 (13.4%) were seeking or awaiting diagnosis. The combination of professional/medical diagnosis and self-diagnosis = 129 (86.6%).

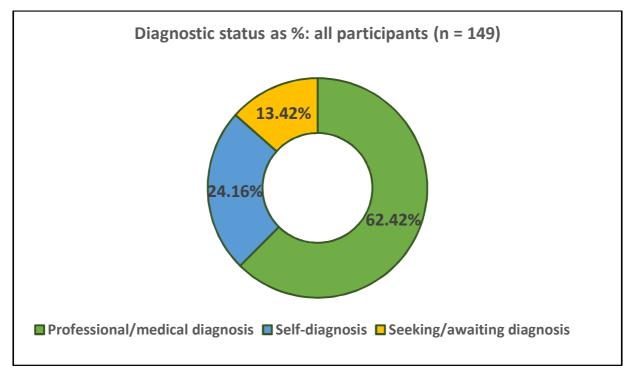


Figure 1: diagnostic status of all participants (n = 149) as a %

- c. Age of diagnosis: 106 participants, including some who were self-diagnosed, provided an age at which they were diagnosed as autistic. The age range was from 2 60 years; the median was 34.5 years.
- d. All 93 participants who had a professional/medical diagnosis of autism provided an age at which they were diagnosed. For them, the age range was from 3 – 60 years; the median age was 34 years. Only six participants who had a professional/medical diagnosis were diagnosed under the age of 18.
- e. **Biological sex**: 119 (80%) of participants were female; 30 (20%) were male.
- f. Gender identity. Of the 136 responses, 98 (72%) identified as female; 27 (20%) identified as male; 5 (4%) identified as non-binary; 4 (3%) rejected concepts of gender; 1 identified as a non-binary woman; 1 identified as agender.
- g. **Employment status (any).** At the time of completing the survey, 130 (87.25%) of participants had a job; 19 (12.75%) did not have a job.

h. Employment status (schools/education): 49 (33%) of all participants had worked in a school in the past in an education role, but were no longer working in a school at the time of completing the survey; 100 (67%) of all participants were working in a school in an education role at the time of completing the survey.

ONE THIRD OF PARTICIPANTS WERE NO LONGER WORKING IN A SCHOOL AT THE TIME OF COMPLETING THE SURVEY.

Point 4: information provided by participants who no longer work in a school (n = 49)

Point 5: information provided by participants who work in a school now (n = 100)

4. PARTICIPANTS NO LONGER WORKING IN SCHOOLS

n = 49

a. 48 participants provided information on the roles they had had in schools. The most common, recent or predominant role for participants was teacher (n = 20), one of whom had also been a SENCO (Special Educational Needs Co-ordinator). This was followed by teaching assistant (n = 19) trainee teacher (n = 3), Headteacher (n = 2), assistant or deputy Headteacher (n = 2) and nursery nurse (n = 1). One participant had worked in an alternative education role (not stated here in order to protect identity). Some participants had had a number of different roles in their school education career.

MOST PARTICIPANTS WHO NO LONGER WORK IN A SCHOOL HAD BEEN A TEACHER OR A TEACHING ASSISTANT. HOWEVER, SOME PARTICIPANTS HAD HAD A NUMBER OF DIFFERENT ROLES IN THEIR SCHOOL EDUCATION CAREER.

b. Participants were asked **who, in relation to their work in schools, knew about their autism diagnosis**. They could choose as many answers as they liked from pre-set answers and also had the option to provide individualised or additional information in a box marked 'other'. All 49 participants provided a total of 68 responses.

Pre-set options:

No-one (n = 27) (40%)

My Headteacher/line manager (n = 14) (21%)

My colleagues (n = 10) (15%)

Pupils (n = 4) (6%)

Pupils' parents (n = 1) (1%)

The main response in the 'other' (n = 12; 18%) category was that the participant was not diagnosed at the time of working in a school (n = 7).

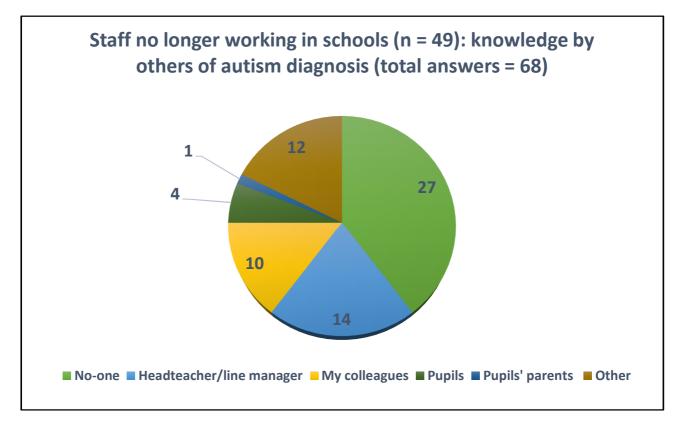


Figure 2: knowledge by colleagues, parents and pupils of autism diagnosis of staff no longer working in a school (total responses = 68)

40% OF PARTICIPANTS WHO NO LONGER WORK IN SCHOOLS SAID THAT NO-ONE KNEW ABOUT THEIR AUTISM DIAGNOSIS.

c. Participants were asked **why they no longer work in a school**. They were provided with set reasons as well as an 'other' option: they could choose as many as they wanted. All 49 participants provided a total of 173 responses/reasons.

Most common responses from pre-set options:

Impossible to work/burnout (n = 26) (15% of total responses)

A difficult work environment e.g. noise, lighting etc. (n = 20)

Lack of support from employer (n = 19)

Excessive workload (n= 15)

Lack of flexibility from employer (n = 13)

Lack of understanding from employer about autism (n = 10)

Unable to be open about being autistic (n = 9)

Poor pay (n = 8)

Lack of understanding from colleagues about autism = 7

The main reason from the 'other' option (n = 29; 17% of total responses) was anxiety/mental and/or physical health issues (n = 7).

THE MOST COMMON REASON PROVIDED BY PARTICIPANTS FOR NO LONGER WORKING IN A SCHOOL WAS THAT THEY HAD FOUND IT IMPOSSIBLE TO WORK DUE TO BURNOUT. THEY ALSO FOUND SCHOOLS TO BE A DIFFICULT WORKING ENVIRONMENT IN TERMS OF NOISE, LIGHTING ETC., THAT THERE WAS A LACK OF SUPPORT FROM THEIR EMPLOYER AND A LACK OF UNDERSTANDING ABOUT AUTISM FROM THEIR EMPLOYER AND COLLEAGUES.

d. Participants were asked to choose from set options in order to indicate whether being autistic was a help or a hindrance in their work in schools. Responses from all participants (n = 49), followed by a percentage were as follows:

Being autistic was both a help and a hindrance in my job (n = 35) (71%)

Being autistic helped me in my job (n = 6) (12%)

Being autistic was a hindrance in my job (n = 5) (10%)

Being autistic neither helped nor hindered me in my job (n = 3) (6%)

THE MAJORITY OF PARTICIPANTS WHO NO LONGER WORK IN A SCHOOL CONSIDER THAT BEING AUTISTIC WAS BOTH A HELP AND A HINDRANCE IN THEIR JOB.

5. PARTICIPANTS WHO WORK IN A SCHOOL NOW

n = 100

a. All participants (n = 100) provided information on their current job in a school. Teachers were the largest cohort (n = 51); followed by teaching assistants (n = 21); SENCOs (of whom one was also a teacher and another was also a deputy Headteacher and so they have been counted twice) (n = 8); Head of Department (n = 7); other/therapeutic support (n = 7); members of the Senior Leadership Team (including deputy Headteacher) (n = 3); Headteacher (n = 2); trainee teacher (n = 2); Early Years Practitioner (n = 1).

JUST OVER HALF OF PARTICIPANTS WHO WORK IN A SCHOOL NOW ARE TEACHERS. HOWEVER, PARTICIPANTS OVERALL HAVE A RANGE OF ROLES INCLUDING TEACHING ASSISTANT, SENCO, HEAD OF DEPARTMENT AND HEADTEACHER.

b. Participants were asked who, in relation to their work in schools, knows about their autism diagnosis. They could choose as many answers as they liked from preset reasons, and also had the option to provide individualised or additional information in a box marked 'other'. All 100 participants in this category provided 194 answers:

My Headteacher/line manager (n = 53) (27%)

My colleagues (n = 45) (23%)

No-one (n = 35) (18%)

Pupils (n = 24) (12%)

Pupils' parents (n = 15) (8%)

From the 'other' category (n = 22; 11%), most emphasised the need to share this information with a small number of trusted colleagues (including specialist colleagues such as the SENCO) or parents only.

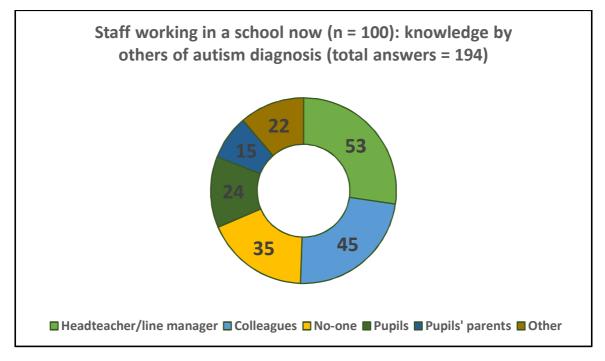


Figure 3: knowledge by colleagues, parents and pupils of autism diagnosis of staff working in a school now (total responses = 194)

IN CONTRAST TO THE PARTICIPANTS WHO NO LONGER WORK IN A SCHOOL, 50% OF PARTICIPANTS WHO WORK IN A SCHOOL NOW SAY THAT THEIR HEADTEACHER, LINE MANAGER OR THEIR COLLEAGUES KNOW ABOUT THEIR AUTISM DIAGNOSIS.

c. Participants were asked **what would make their work in school easier or better**. They were provided with set reasons as well as an 'other' option: they could choose as many as they wanted. A total of 432 responses were provided by 99 participants in this category.

Most common responses from the set options:

A better work environment e.g. less noise, different lighting etc. (n = 61) (14% of total responses)

Being able to be open about being autistic (n = 51)

A more manageable workload (n = 49)

More understanding from colleagues about autism (n = 47)

More understanding from employer about autism (n = 44)

Greater flexibility from employer (n = 42)

More support from employer (n = 33)

Better pay (n = 28)

More support from colleagues (n = 23)

More external support (e.g. social services, counselling) (n = 23)

From the 'other' category (n = 18; 4%), the main suggestions included better adjustments and accommodations (n = 4) and clearer/less ambiguous communication from colleagues (n = 4).

WHEN ASKED WHAT WOULD MAKE THEIR WORK BETTER, THE MOST COMMON ELEMENT FOR PARTICIPANTS WHO WORK IN SCHOOLS NOW IS THE PROVISION OF A BETTER WORKING ENVIRONMENT IN TERMS OF LESS NOISE, DIFFERENT LIGHTING ETC. THE SECOND MOST COMMON ELEMENT IS BEING ABLE TO BE OPEN ABOUT BEING AUTISTIC.

Participants were asked to choose one option from the following (responses from all participants [n = 98] in brackets):

Being autistic both helps and hinders me in my job = 76(78%)

Being autistic helps me in my job = 17 (17%)

Being autistic is a hindrance in my job = 3(3%)

Being autistic neither helps nor hinders me in my job = 2(2%)

LIKE THE PARTICIPANTS WHO NO LONGER WORK IN A SCHOOL, THE MAJORITY OF PARTICIPANTS (78%) WHO WORK IN A SCHOOL NOW CONSIDER THAT BEING AUTISTIC IS BOTH A HELP AND A HINDRANCE IN THEIR JOB.

6. ALL PARTICIPANTS

All participants were asked to indicate how much they usually enjoy, or used to usually enjoy, their work in schools, by choosing on a scale between 1 - 5 (1 = very little; 5 = very much).

n = 146

- 4 participants selected 1
- 10 participants selected 2
- 40 participants selected 3
- 60 participants selected 4
- 32 participants selected 5

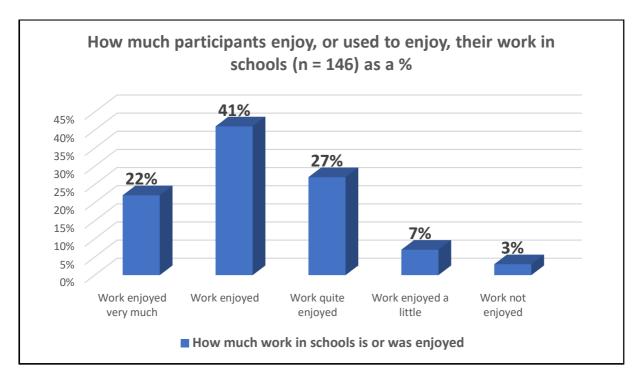


Figure 4: how much all participants enjoy or used to enjoy their work in schools (n = 146) as a %

THE MAJORITY OF ALL PARTICIPANTS (63%) EXPRESSED A HIGH DEGREE OF SATISFACTION WITH THEIR WORK IN SCHOOLS. Finally, participants had the option, in an open question, of providing any further information or points they wished to make in keeping with the overall theme of the survey. 90 participants provided answers: these will be analysed in more detail over the coming months, but responses have been grouped into the following, initial codes or categories (Saldaña 2016):

- 1. Enjoyment/love of job
 - a. Especially in support of autistic pupils
- 2. Support
 - a. Colleagues can be supportive versus
 - b. Lack of support/understanding from management/employer and
 - c. Lack of reasonable adjustments
- 3. Predictability/structure/routine
 - a. Aspects of the job provide this and this is valued
 - b. Aspects of the job don't and this is problematic
- 4. Othering
- 5. Masking
 - a. Fear of revealing true self, especially in times of stress
- 6. Anxiety
 - a. Linked with stress
 - b. Fear of making mistakes
- 7. Sensory issues
 - a. Noise
 - b. Crowds/busy environment of school
 - c. Other e.g. hot, smelly classroom
- 8. Difficulty in reading others/understanding unspoken meanings
- 9. Disclosing diagnosis
 - a. Generally this is feared
 - b. Disclosure did not always help
 - c. Sometimes disclosure has been positive for the individual and the school
- 10. Lack of understanding about autism is problematic
- 11. Link between job and 'special interests' (usually positive)
- 12. Fatigue/burnout
- 13. Considered to be good/outstanding/excellent at job
- 14. Differences between schools in terms of understanding and support provided

7. KEY POINTS

- A little under two thirds of all participants had a medical/professional diagnosis of autism. The rest were either self-diagnosed, or were seeking/awaiting a diagnosis.
- The median age of diagnosis 34 was relatively high. Nearly all participants were diagnosed in adulthood.
- The biological sex of 80% of participants was female.
- 40% percent of participants who no longer work in schools said that no-one knew about their autism diagnosis. However, 50% of those who work in a school now said that either their line manager or colleagues know about their autism diagnosis.
- Although many participants were teachers (n =71; 48%) or teaching assistants (n = 40; 27%), a range of education roles, including senior management and school leadership, were represented in this sample.
- The main reason provided by participants for no longer working in a school was that they had experienced burn-out. However, many other reasons were cited.
- The most common factor that would make the work easier for participants who work in a school now would be a change in the environment. However, a number of other factors were also cited.
- The majority of all participants said that being autistic was both a help and a hindrance in their work in schools. 15% of all participants said that being autistic helps or helped them in their work. 5% of all participants said that being autistic was a hindrance in their work.
- The majority of all participants expressed a high degree of satisfaction in their work.

8. NEXT STEPS

Participants had the option of providing an email address in order to be potentially interviewed in the future to explore the issues covered in this survey in greater depth. Over 80 participants provided an email address: the next step will therefore be to organise this stage of the project.

References

Convention on the Rights of Persons with Disabilities (2006), United Nations. Accessed on 15/07/2014 at http://www.un.org/disabilities/convention/conventionfull.shtml

Hendricks, D. (2010) 'Employment and adults with autism spectrum disorders: Challenges and strategies for success.' *Journal of Vocational Rehabilitation 32* (2010): 125-134.

Saldaña, J. (2016) *The Coding Manual for Qualitative Researchers,* 3rd ed. London: Sage Publications Ltd.

Wood, R. (2019) *Inclusive Education for Autistic Children: Helping Children and Young People to Learn and Flourish in the Classroom.* London and New York: Jessica Kingsley Publishers.

Acknowledgements

With gratitude to all participants who completed the survey and provided their valuable input and views. Thanks also to Kabie Brook of Autism Rights Group Highland (ARGH), for the members of ARGH who supported this project, and for colleagues and associates who kindly distributed the survey. Particular thanks to the members of the autistic committee – Alan Morrison, Elkie and Malcolm Hamilton - who provided important feedback and essential suggestions when the survey was being developed. Many thanks to Dr Laura Crane of the Centre for Research in Autism and Education at University College London for her helpful comments on an earlier draft. This project was funded initially by the ESRC (ES/S011161/1).

Report written by Dr Rebecca Wood, Senior Lecturer in Special Education, University of East London and visiting Research Fellow at King's College London. Visiting Research Fellow, University of Birmingham. Contact: rwood@uel.ac.uk

Project Mentor: Professor Francesca Happé, Professor of Cognitive Neuroscience, Social, Genetic and Developmental Psychiatry Centre, King's College London.

March 2020