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| **Title:** | **The ‘High Achievers’ Project: An assessment of the support for students with autism attending United Kingdom universities** |
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**Abstract**

In the United Kingdom autism is classed as a disability under the Disability Discrimination Act, 2005. Under the Special Educational Needs and Disability Act, 2001, higher education (HE) institutions in the UK are legally required to make reasonable adjustments for students with disabilities who are placed at a substantial disadvantage in comparison to students without disabilities. Despite the social difficulties associated with autism, and autistic students being at a heightened risk of dropping out of university, high-functioning autistic students are often high achievers academically. The National Audit Office recognises university as a desirable option for academically gifted students with autism. As there have been few studies directly examining the needs of autistic students in post-secondary education by established researchers, we undertook an online questionnaire survey of all UK universities, other than those under foreign ownership, to ascertain current levels of support for students with autism in HE. We report our findings based on responses from 99 universities out of c160 establishments in total. As autistic university graduates are at a disadvantage to their non-autistic peers in obtaining employment after graduation, we propose that all HE establishments follow the Government recommendation for providers of services not covered by the Autism Act, 2009, but who support people into employment, to adopt the Statutory Guidance issued in connection with the Adult Autism Strategy. Universities should consider seeking accreditation under the National Autistic Society’s accreditation scheme.

**Introduction**

As one of us wrote in an introduction to an article in this journal on students with autism in further education (FE), autism was described as ‘social dyslexia’ because the disabling effects it has on social interaction and communication are analogous to the disabling effects of dyslexia on the ability to read and write (Howlin, 2003). Autism consists of a spectrum of pervasive developmental conditions involving delays in social interaction, social communication, and social imagination (World Health Organization 1992; American Psychiatric Association 1994). Many individuals with autism[[1]](#footnote-1) also have one or more sensory sensitivities. Asperger syndrome (AS) is one of the diagnoses on the autism spectrum. Individuals with AS and high-functioning autism have average or above-average intellectual ability. In this article the term ‘autism’ covers all autism spectrum diagnoses.

The current legislation covering disability in the United Kingdom is the Equality Act (2010), which superseded the Disability Discrimination Act (DDA) 2005, and the Special Educational Needs and Disability Act (SENDA) 2001. Autism is classed as a disability under the DDA. Higher education (HE) institutions in the UK are legally required under SENDA to make reasonable adjustments for students with disabilities who are placed at a substantial disadvantage in comparison to students without disabilities.

Despite the social difficulties associated with autism, high-functioning autistic students are often highly capable intellectually (Van Hees, Moyson and Roeyers, 2015). The Cambridge Asperger Syndrome student project wrote that students with Asperger syndrome (AS) at university: ‘are by definition very high achievers and the NAO 2009 report recognises university as a desirable option for academically gifted students with AS’ (Hastwell et al., 2013, p.4). The percentage of students with autism is increasing year on year. The Higher Education Statistical Agency has recorded a rise of 77% in the number of students identified as having autism in UK Universities in the three years to 2010-11.[[2]](#footnote-2) Applications to the University of Cambridge from students with AS increased by 219% over the five years to 2012/13. Not surprisingly, given the social difficulties in autism, the National Audit Office (2009, pp. 30/31) stated that ‘One issue frequently highlighted by people with autism, carers and disability advisors in our web consultation and focus groups was that students with autism may need more support with the social side of university … than with purely academic, course-related matters’. With knowledgeable support, students with autism can and do succeed at university but such support has been considered to be a rarity in post-secondary education in recent times (Breakey, 2006). However, there have been few studies directly examining the needs of autistic students in post-secondary education by established researchers (Ying Cai and Richdale, 2015), although we have noticed that a few recent doctoral dissertations have focused on the needs of students with autism in both HE and FE which is an excellent sign (Bruce, 2014; Ciccantelli, 2011; Wiorkowski, 2012).

Van Hees, Moyson and Roeyers (2015, pp. 1673/4) write: ‘Although students with [autism] have the potential to perform well academically, they are at a heightened risk for academic and personal failure during the college years’. To overcome this risk, they state that ‘universities and colleges must provide appropriate interventions and supports that differ from those provided for students with other types of disabilities’. Support for the social aspect of university life is a high priority, with students (at a Belgian university) who participated in the interviews carried out by these authors referring to the “exhausting but necessary social contacts”, “difficulties managing social demands”, “awareness of social problems”, and the contribution of social difficulties to “mental health issues”.

**The ‘High Achievers’[[3]](#footnote-3) survey of United Kingdom universities**

We had two specific objectives in mind for our survey to better understand the current level of support for students with autism studying at UK universities. Firstly, we wanted to understand the extent to which universities in the UK comply with disability discrimination law as regards students with autism. Secondly, we thought that in doing so we might also identify examples of best practice and develop recommendations aimed at raising standards across the HE sector in the context of autism. Underlying this was a view that an autism-appropriate approach to supporting students with autism would better enable them to fulfil their academic potential, improve their university experience, and move on in their lives successfully after university. Such an approach would enhance the reputation of a university, leading to recruitment of more students with autism with the potential to make a significant contribution to raising standards of academic attainment (Hastwell et al., 2013).

We now explain the initial ‘key’ decision-making, and our approach to data collection (including questionnaire design) and analysis, before setting out our findings, highlighting the strengths and weaknesses of current provision identified by our respondents.

***Methods***

To avoid the risks associated with generalising from a sample to the total population, we decided to seek contributions to our study from *all* UK universities other than non-UK owned campuses (to maintain a fully UK focus). We also excluded colleges that grant degrees. We decided on a questionnaire survey rather than interviews given the logistical ‘impossibility’ of interviewing representatives of about 160 establishments. (We aim to undertake a follow-up study involving interviews subject to obtaining the necessary funding[[4]](#footnote-4) to facilitate this.) A two phase data collection stage was adopted involving the submission of a questionnaire to university disability support teams followed by the submission of Freedom of Information Act (FOIA) requests to universities that did not complete the questionnaire. The question set was deliberately left unchanged for the second phase, despite the opportunity to make changes, to enable like-for-like comparisons. As respondents to the initial survey would be volunteers, but there was a legal requirement to complete FOI requests, we decided to analyse the data in three stages – the first phase data set, the second phase data set, and the two sets combined – and identify any significant differences between the first two data sets. Finally, we undertook a ‘pilot’ exercise with a couple of university disability officers to test out the original questionnaire design, making minor changes to reflect feedback received.

We undertook the FOI phase of the project in accordance with the FOI Act 2000, the FOI (Scotland) Act 2002, the guidance for using FOI Act requests in an academic context issued by University College London (UCL) (Bourke, Worthy, and Hazell, 2012), and the guidelines issued by the Information Commissioner's Office (ICO). We ensured Data Protection Act compliance. As privately owned establishments are not subject to the FOIA, we could not submit requests to *all* the universities contacted during the first phase.

We now turn to the design of the questionnaire. All researchers using the questionnaire survey method wrestle with the need to balance the wish to ask questions with the risk of discouraging participation. This issue assumed a greater priority for us because exemptions in the FOI Act enable organisations to avoid responding either to individual questions or to an entire request. Refusal is justified if it would cost too much or take too much staff time to deal with a request, or if a request is considered vexatious. It was therefore essential to keep the number of questions in the FOI request to a necessary minimum to manage the risk of requests being refused. As we had decided to use the same question set for both data collection phases, this imperative did not just affect the design of the FOI requests. We decided to ask no more than 20 specific questions. In most cases, questions were our approach to seeking information relevant to matters referred to in the Final Project Report of the Cambridge Asperger Syndrome Student Project, 2009-12 (Hastwell et al., 2013). We also provided space for respondents to provide additional freeform comments.

***Lessons learned***

During the course of the FOI phase of our data collection activity, we learned various lessons which we describe here briefly as they may assist other academic researchers who decide to use FOI requests as an academic research tool.

We were initially unaware that the chosen online survey tool did not have the facility to enable universities to retain a copy of their online submission for subsequent reference. This proved to be an issue as recipients of FOI requests are required to retain a copy of their responses in their records in accordance with section 8(1)(a) of the FOI Act[[5]](#footnote-5).

We sought to reflect the guidance issued by the ICO and UCL in undertaking the FOI phase of our data collection exercise. As the sheer scale of the survey prevented us from building a relationship with each university FOI officer, we decided that the least we could do to assist them was to provide them with advance notice of our intention to submit an FOI request. This approach proved very useful to some establishments.

One respondent explained the position regarding data protection vis a vis FOI requests undertaken for academic research purposes: ‘While it may not be your intention to publish data which could be used to identify individual members of staff, all disclosures under FOI must be considered as disclosures to the general public and not to an individual’.

We strongly recommend academic researchers using FOI requests to trial their request as they would any other survey to ensure, as far as possible, that it will not fall foul of any of the exemptions within the FOIA. Whilst an FOI request has the advantage of statutory backing, so response rates should be close to 100%, a high response rate may only be achievable if researchers ensure that they comply with the terms of the FOIA and avoid the possible application by recipients of one of the exemptions built into the Act.

***Results***

We received responses to the survey from 99 establishments which represented about 60% of the total number of universities in the UK. Individual universities did not always respond to all questions, hence the total number of responses to a question is often less than 99.

Of the 99 respondents to the survey, 84 provided figures in response to the question asking how many students declared an autism spectrum diagnosis during each of the previous five academic years, but not all respondents provided figures for each year. Although the totals cannot be exact[[6]](#footnote-6) (e.g., some ‘rounded’ figures were likely to be estimates), we now know that approximately 4,668 students had declared a diagnosis of autism in the academic year 2014/15 to the 84 establishments that responded, which is a substantial number. There are 55 students with autism on average in each university, although the numbers reported varied from one to ‘approximately 200’ per establishment with ten universities having more than 100 autistic students on their role in 2014/15 and another 24 establishments having between 50 and 99 students in that same year. The number of establishments reporting figures between 2010/11 and 2014/15 varied substantially (from 47 to 84) so that direct comparisons between all these years were not possible. However, the variation in numbers of establishments reporting from 2011/12 to 2013/14 was only three (70, 72 and 73) so the percentage increase in the number of students over these three years of 53% (2,045 to 3,129) was for almost directly comparable university numbers. On the basis of a pro rata increase from 2010/11 to 2011/12, and a pro rata increase between 2013/14 and 2014/15, we estimate that the student population declaring a diagnosis of autism increased over the four years from 2010/11 to 2014/15 by 124% *on a like-for-like basis[[7]](#footnote-7)* which is a substantial change over a relatively short period (especially when considered in the light of the 77% increase in the three years to 2010/11 reported by Hastwell et al. (2013)). This suggests that the overall percentage increase from 2008/09 to 2014/15 in numbers of students with autism in HE may have exceeded 200%. The actual numbers of autistic students attending UK universities will be significantly greater than the figures reported to us as some students will not have declared their diagnosis and others may not know that they have autism.

Of the establishments not providing student numbers, 12 stated that they do not hold the information at all, do not hold it in the form requested (e.g., their data holdings are insufficiently specific), or that a physical search of individual student files would be necessary. A further university was unable to provide the data as they were transitioning student record programs. One university stated that the cost of locating and extracting the data would exceed the FOIA cost threshold which implied that this establishment did not hold the data requested online. Another university wrote that the provision of this data is exempt under Section 40 (2) of the FOIA because the low numbers of students involved would risk identifying individuals so that disclosure might breach data protection principles.

All but one of the 99 respondents answered our question asking if they have an in-house autism expert/specialist to provide their staff with advice on supporting students with autism (both academically and pastorally). 40 (40%) of the respondent universities had no in-house autism expert/specialist[[8]](#footnote-8), 28 (28%) had one in-house specialist, and a further 31 (31%) had more than one in-house specialist. Of the 59 respondents who had at least one in-house autism expert/specialist, 37 (63%) employed their specialist(s) on a full-time basis[[9]](#footnote-9), 17 (29%) employed them on a part-time basis, and five (8%) had both full-time and part-time staff. There is a clear preference (71%) for employing at least one full-time autism specialist.

A further question requested details of the qualifications of autism specialist(s). Three universities withheld responses to avoid the individual being identified. One respondent referred to data protection as justification for not responding to this question. Another establishment provided a link to their website showing their adviser’s qualifications; needless to say, the individual concerned is highly qualified (doctorate, chartered psychologist etc.). A further university wrote that ‘There is little in the way of formal qualifications in this area [autism]’. Other respondent universities employed autism specialists with formal HE level qualifications in autism and/or Asperger syndrome from at least four different establishments. We counted 12 individuals with a Postgraduate Diploma/Certificate in Autism and/or Asperger Syndrome, one Doctorate, two with a Masters in Autism, and one BPhil in Autism. In addition, a further respondent employed a number of advisers with both a PG Cert in Autism from one university and a PG Cert in Asperger Syndrome from a second university, although it was unclear how many advisers they had. In total, there appeared to be about 18 individuals qualified in *autism* across the 63 establishments employing in-house specialists[[10]](#footnote-10). We conclude the comments on the matter of qualifications by quoting the establishment which defined its academic requirements for autism specialists as follows: ‘The specialist roles listed … require at least a first degree or equivalent, knowledge and understanding the needs of disabled students, relevant and significant experience of delivering advice and support, and working within a FE/HE environment’ but there is no mention of *autism*.

We also asked what arrangements are made when a university requires specialist expertise in autism but does not have an autism expert/specialist on staff. Responses included: ‘We ask the student (and involve other agencies if necessary) what is going to work best for them’; accessing services from the National Autistic Society, regional autism organisations, or via the National Association of Disability Practitioners; and using the services of a local autism specialist. One respondent university – and bear in mind that this question related to universities *without* an in-house autism specialist – stated ‘we get external support where necessary (esp for staff training) but to be honest we find the external “experts” are not always much more knowledgeable or experienced as ourselves’.

We asked three specific questions concerning provision of training and refresher training in autism’, one relating to new disability support staff and student mentors, a second relating to non-teaching staff other than disability support staff and mentors, and a third relating to new academic staff. Responses to each question varied considerably. Only 12 of the respondents to the question relating to disability support staff training appeared to provide some compulsory training; as far as we could tell, only one establishment provided compulsory training for academic staff; and none of the respondents to the question relating to other non-teaching staff stated that any training was compulsory (although there were mentions of activities such as a ‘disability day’ at the point of induction, which we presume all staff are required to attend, we did not classify these as ‘compulsory training’).

One respondent provided training to their autism mentors via weekly mentoring group meetings. Many respondents referred to ‘offering’ training, training being ‘open’ to academic staff, to providing training ‘on request’, or to training being ‘available’. Some training was only provided online. In a few cases an establishment made achieving a Postgraduate Certificate in HE – which included a session on Asperger syndrome awareness – compulsory for all teaching staff. One establishment stated their position that working with academic departments in support of individual students was an effective approach. Another university’s response to the question relating to academic staff was ‘(the university) doesn’t do “mandatory”, which is a shame’. A further establishment stated that ‘training is offered to all academic staff but it is not mandatory so we have found that very few staff attend’. Yet another respondent stated that they had never been asked to provide training for their academic staff (why did they have to wait to be asked?). One university advised that training and refresher training in autism for staff supporting students with autism‘is offered but not usually taken up’ which was of concern to us. Quite a few responses mentioned ‘General disability awareness training’ and ‘general equality training’ which may include some autism content. A lecturer in autism at one establishment had provided autism awareness training as part of wider disability training for all three categories of staff for the past three years.

All bar one of the 99 respondents answered the question asking what form support for students with autism takes, although one response had to be excluded because it was impossible to interpret. The numbers of universities providing each of the listed areas of support, and the relevant percentages that the numbers providing support bear to the total number of included respondents (97), are shown in Table 1 below. We list the areas of support in percentage order (commencing with the highest percentage).

**Table 1: Support provided for students with autism at university**

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|  | **Choices (respondents can tick as many of these as apply)** | **No** | **%** |
| 1 | Can students stay in halls for the duration of their study? | 89 | 92 |
| 2 | Extra face-to-face tutorial time and/or email contact time with tutors/mentors? | 88 | 91 |
| 3 | Provision of scribes and/or audio recordings of lectures | 87  | 90 |
| 4 | Preference for halls of residence (if requested) | 85 | 88 |
| 5 | Extended submission deadlines | 73 | 75 |
| 6 | Support in accessing access learning centres and IT | 70 | 72 |
| 7 | Support for applicants with autism when attending for interview? | 66 | 68 |
| 8 | Assistance in travelling to and from different locations in the university  | 57 | 59 |
| 9 | Befriending scheme[[11]](#footnote-11) | 47 | 48 |
| 10 | Arrangements to ensure continuity of tutors between years as far as possible | 38 | 39 |
| 11 | Lectures/tutorials for courses with a high percentage of students with autism scheduled to take place in the same building/room as far as possible | 27 | 28 |
| 12 | Is there a dedicated section in the prospectus outlining support available for persons with autism and who to contact for further information?[[12]](#footnote-12) | 21 | 22 |

As expected, the support provision percentages were, for the most part, substantially similar between the responses to the original survey and the later FOI request responses. However, there were significant differences between the respective percentages relating to: scribes and/or audio recordings of lectures (59% for the survey, 94% for the FOI requests); extended submission deadlines (53% / 78%); a dedicated section in the prospectus (35% / 19%); and for travelling assistance (29% / 64%). We cannot explain these differences.

There was no consistency between the universities responding to our follow-up question regarding the means used to obtain feedback on the effectiveness of the support provided for students with autism. Virtually all the respondents answered this question. Responses covered a range of mechanisms including: use of feedback forms; the National Student Survey; individually tailored disability support surveys; discussion during mentoring sessions; monthly reviews; 1-2-1 sessions; case reviews; an online student feedback system; an automated email campaign; a suggestion box; interviews of students going through the university’s specialist autism induction course; student focus groups (the university concerned is also trying to launch a disabled students’ forum); and verbal feedback through support workers. One university recruited a pool of students[[13]](#footnote-13) who could attend their Disability Working Group chaired by a director. At the other end of the scale, the full response from another establishment was ‘Our Mental Health Coordinator[[14]](#footnote-14) will invite students to come and discuss any issues that might arise on a regular basis’. This particular university did not know how many students with autism were enrolled, did not have an autism specialist on its staff, apparently fails to appreciate that autistic students may not want to call attention to themselves by going to see someone.

A further follow-up question asked how the universities acted on feedback to ensure that support continually evolves and meets the needs of the students. Almost all the respondents answered this question. Responses included: updating service level agreements based on feedback received; feeding information into the content of training courses for staff; annual and ad hoc reviews of policies and procedures in response to feedback; building feedback into the university’s planning process; and a process of ‘constant’ evaluation and improvement. One university responded: ‘Peculiar question. How do you act on feedback? Hopefully by listening and adjusting provision’; the fact that they answered their own question rather suggests that there was a point to our question, and other establishments listed a variety of ways and means of adjusting support provision. One standout response, worth quoting in full was: ‘Feedback is monitored, analysed and reported to the Disability Working Group, which has the task of monitoring disability provision, and is fed into the Service's Operational Plan. Information on improvements is published on our webpages and in our Annual Review. Our feedback systems are aligned to the Matrix Quality Standard’. This is the same establishment that recruits students to attend their Disability Working Group.

In response to the question asking about arrangements made for new students with autism transitioning from school or college, a significant number of establishments have extensive transition/induction/residential orientation programmes prior to a student’s arrival date, and it seems generally the case that many universities understand the need for support both prior to starting as well as during their stay. Some pre-entry events are open to the student’s parent or carer (which may be important for an autistic student). Apart from those establishments not offering undergraduate qualifications, only two universities stated that they provided no support at all to students with autism transitioning in from school (although there was a great deal of variation between responses). One minimalist response was ‘depends on student need - peer mentoring available (sic), Learning support agreements to make faculty aware, NMH support front loaded to cover transition’ which appears focused on support in the early days at university with no specific mention of pre-arrival support. Another university referred to ‘transition arrangements’ without specifying what the arrangements were. Elsewhere, transition programmes are said to be held over one, two or three days, and include open day events, campus visits, meetings with tutors/supervisors etc. Universities also mentioned provision of buddy support, enrolment prior to starting; 1-2-1 assistance for students with high anxiety ‘during freshers’ week’, and setting aside a quiet room ‘on the first day of fresher week’ (it was unclear why this is only on offer on the first day but maybe students with autism are encouraged to attend that day only), working with schools prior to starting (when permission is granted), meetings with disability advisers, learning support agreements, regular emails over the summer with information and advice, and mentoring support. Some establishments encourage applications for Disabled Student Allowance (DSA) ‘well in advance of starting the course to ensure all support is fully implemented before arrival’ (to quote one respondent). One university mentioned the provision of a transitional learning contract where DSA is not in place from the start. One establishment set out the following long list of supports: ‘A summer school is available prior to the start of term, campus tours with Student Ambassadors, a Setttling-in (sic) Group, Meetings with the Disability Co-ordinator, a Learning Support Plan with details of adjustments/arrangements needed, meetings with Mentors’. Another example of an especially comprehensive response was:

Pre-offer/entry contact with applicants who have declared Autism on their application to set up support. Annual Summer School, 2 night residential free of charge to applicants to prepare them for the transition to University. This includes workshops for parents or other significant relationships We offer individual visits to site and tours Individual open day appointments Links with local Special Needs School. Students with autism who are moving into halls receive a letter providing a named contact and an offer to contact or visit frequently before they move into the accommodation Get Ahead Event – before main enrolment in September students can arrive early to Halls/enrol and a programme of preparatory workshops, including 1-1 meetings to arrange support.

One university’s innovative approach to early ‘transitioning’ from school was to train a cadre of its students to mentor school pupils with university potential ‘from Year 9+ onwards’.

Although we referred to training in relation to raising awareness amongst university staff, we asked about *arrangements* in relation to the peers of students with autism, it being a matter of ongoing debate as to whether or not autism awareness training should be delivered to non-autistic students. One university stated that if a student wished their classmates to be aware of their autism the university would prefer that the student talked to their peers about their personal experience of autism, rather than that the university deliver training. Other establishments drew attention to the, often difficult, issue of disclosure of autism to peers, generally as a reason not to provide awareness training unless specifically requested by the student to do so. One respondent wrote ‘Most (autistic students) do not want their autism discussed or highlighted to fellow students’. (Autism awareness training can be delivered without students being identified). In some cases, awareness arrangements were targeted at classmates or flatmates of autistic students living in Halls of Residence. Forty three of the respondents either had no provision at all or responded ‘available on request’ or similar. Generally speaking, establishments that did make arrangements often relied on raising general disability awareness. Autism-specific approaches included: a student autism society working with the students union; an autism group having its own social media channels promoted via main channels; the university’s students association taking part in an autism transition programme; awareness campaigns and events; awareness training for student mentors; buddy arrangements between an autistic student and a non-autistic student sharing accommodation; awareness events (some linked to World Autism Awareness Day); publishing information on autism on their website; information leaflets; and including autism awareness questions in disability quizzes open to all new students. One university stated: ‘Some training but not enough offered in this area’. Another said that it was a ‘long term priority’ to develop arrangements for raising awareness of autism.

Only one respondent stated that they had a specific autism policy. Six respondents said they had made specific provision relating to autism in their general equality/disability policy. On checking with the establishment that said they had a policy on autism, it became apparent that they were referring to a section regarding support available for students with autism on their website, and that this was not an official University policy. We reviewed the relevant policies for the establishments which said they had made specific provision for autism in their equality/disability policy and found no reference to autism in any of the policies. It was then clear to us that the nature of our questions relating to policy had been misunderstood by these seven universities. The strong indications are that no respondent had a separate autism policy or made provision specific to autism in their generic equality/disability policy.

We hoped to be able to draw conclusions about graduation rates for students with autism in comparison to the total student body. However, we are unable to do more than draw attention to a few points because of the small amount of data provided. Of the 99 universities that responded to the survey, only 21 could provide graduation comparison data for at least one of the five years we were interested in and only eight establishments could provide figures for all five years. The 21 establishments gave us only a total of 57 individual years’ worth of data. Over these 57 years, in 41 years the ‘all students’ graduation rate exceeded that for the students with autism, the situation was reversed in a further 15 years, and in one year the two graduation rates were the same. A small number of establishments had misunderstood the question and had provided comparison data relating to the achievement of a first, 2:1 or 2:2 degree[[15]](#footnote-15), or number of students). It appeared that the universities providing figures for the past five years had at least 50 students with autism in the year 2014/15, and, in most cases, substantially more. Whilst some establishments have too few students with autism for data collection to be worthwhile in the context of comparison with other students, we think that not all universities who should be collecting this data actually are collecting it.

We are unable to do more than draw attention to a few points relating to retention rates due to the limited data provided. Only 29 of 99 respondents, provided retention comparison data for at least one of the five years we requested and only seven establishments provided figures for all five years. The 29 universities gave us only a total of 66 individual years’ worth of data. Over these 66 years, in 42 years the ‘all students’ retention rate exceeded that for the students with autism, the situation was reversed in a further 21 years, and in three years the rates were the same. As with the graduation rate data, it appeared that the universities providing figures for the past five years had at least 50 students with autism in the year 2014/15, and, in most cases, substantially more. Whilst some establishments have too few students with autism for meaningful comparisons to be drawn, it is again correct to state that not all universities who perhaps should be collecting this data actually said they are. In a small number of cases, an establishment quite reasonably stated that the time taken to gather the information would exceed the FOIA “appropriate limit” or risk breaching data protection principles. However, one university stated that it could not provide this information because ‘Disclosure of the requested data would … *be likely to be detrimental to the public interest by calling into question the success of the student experience at (the respondent university)* and the University’s ability to successfully recruit and then retain students on its degree programmes, this would be harmful to the University’s reputation’ (our italics). In this latter case, we question whether disclosure of the data is not in the public interest; specifically, the interest of their potential future students.

We have little to report regarding our question concerning the percentage of students with autism who go on to full-time employment, education or training. This is partly because universities generally rely on the Destination of Leavers from Higher Education (DLHE) survey for this information which, in turn, means that the availability of the information is dependent upon the response rate to the DLHE survey. The small numbers of students with autism at many establishments is often reduced still further as some do not complete the survey. Fourteen universities provided the percentage of their former students with autism who had moved on to employment, further education or training as reported in the latest survey for which figures were available (2013/14). However, the numbers of students involved are generally too small for statistical analysis to be meaningful so we prefer not to report them in detail. For instance, one establishment with over 100 students with autism in 2013/14 provided figures for the years 2010/11 to 2013/14; in two of these years the percentage of former students with autism in employment, further study or both was substantially less than for all leavers, although in the other two years the percentages of leavers with autism actually exceeded the percentages for all leavers (by a small amount). We want to conclude by giving an anonymous mention to the university which, after advising that they do not hold this information, added that they ‘work with students 1:1 either as case managers or mentors to help them manage the transition to post University life’.

We asked those universities which offer qualifications in autism whether the staff teaching these qualifications played any role in raising awareness and understanding of autism across the university. Only five respondent universities had taught autism programmes. The teaching staff at one university offer autism training to staff, another wrote ‘Staff who teach on these courses have provided occasional developmental sessions for other areas of the University in response to requests’, and a third establishment stated that, whilst they did not involve their autism teaching staff in a wider role at present, they hoped to involve them in 2016. One other respondent wrote: ‘as far as I know the teaching staff do not have a role in staff development activities’. Lastly, a university with a major autism centre did not give a direct response to our question, but referred to their ‘ground-breaking scientific research’ in autism. We presume that if their autism team had a wider role they would probably have said so.

In response to the final question asking if they had anything to add, the following key points were made (all the following points have been quoted verbatim from the survey):

1. The government’s proposed policy on DSA support will have a high impact on ASC [autism spectrum condition] students.
2. The Welsh Government suspended the Autism Strategy 18 months ago. We had links with (the Council’s) ASD Development Officer … but believe this post has come to an end.
3. Having a dedicated AS specialist post has made significant impact on the development of support structures here.
4. [The university] had a specialist expert who left last year and hasn't yet been replaced.
5. Support requirements such as copies of lecture notes in advance, permission to record lectures and exam allowances are communicated to staff via a Learning Profile. We also have School Disability Contacts who can act as a point of contact and an advocate for students with ASCs.
6. We run a fortnightly social and support group for ASD [autism spectrum disorder] students which is well attended. The group aims to support the students in developing their social and communication skills … We ask for written consent to liaise with a person chosen by the student (usually a parent) to enable us to maintain contact with those that can offer support … We have a monitoring system to enable us to keep an eye on the progress and wellbeing of students we have identified as being of concern – this includes many of our ASD students …
7. The amount of time you put into autism specific training depends on local resources and most particularly the staff:student ratio in specialist services. Even if I had the knowledge, would I have the time?
8. This year we are looking to set up a transition out of University scheme for students with aspergers to help them with this transition.

We conclude with an honourable mention for the respondent university that advised they were seeking accreditation under the National Autistic Society’s Autism-specific quality assurance programme. We could find no university already accredited under this scheme out of the approximately 480 organisations that have achieved accreditation to date.

**Discussion**

It is difficult to estimate the total number of students with autism at university in the UK. We suspect that a figure of 5,000 in 2014/15 would still significantly underestimate the total number of autistic students attending the 99 respondent universities. As there are in the region of 160 UK degree-awarding bodies[[16]](#footnote-16), there may be as many as 9,000 students with autism in total in UK HE, many of whom are high achievers (Hastwell et al., 2013).

Whilst it is encouraging that 60% of establishments had at least one in-house specialist, and that these are sometimes supplemented by other staff with experience of supporting students with autism, it is of concern that 40% of universities do not currently have any in-house specialist expertise in autism. It is acknowledged that some universities without their own expert employ external advisers; however, this is not necessarily a sufficient alternative to in-house provision as the following statement from one respondent university indicates ‘No [we do not have an autism expert/specialist on staff] but we have a member from ASSIST (Asperger Support Signposting Information Services Team) *who comes in once a month*, whom students can see’ (our italics). We consider it entirely inappropriate to expect a student with autism[[17]](#footnote-17) requiring support to wait up to one month for it.

There are formal postgraduate qualifications in autism available in the UK – including a Postgraduate Certificate in Autism and Asperger Syndrome sponsored by the National Autistic Society – and, clearly, considerable scope for other establishments and individuals to follow the lead of those who have in-house autism-qualified autism specialists.

Of the supports achieving the lower percentages, the inclusion of a dedicated autism section in university prospectuses is surely a potential ‘quick win’ for those establishments yet to provide this support. The size and complexity of university teaching and tutoring arrangements, does make it difficult to ensure continuity of arrangements; however, with the inclusion of an ‘as far as possible’ proviso in our question, we expected higher response rates. Students with autism often have difficulty in finding their way around even one single large, complex building of the type that universities typically consist of, and it should not be difficult to provide such assistance (e.g., though a ‘buddy’ arrangement). So we were surprised that not much more than half of establishments provided assistance in travelling to and from different locations. The ‘inter-campus bus service’ response from one university rather missed the point, as did the establishment which stated that it is a single campus university. These responses stand in direct contrast to the university which referred to ‘helping a student *to use the shuttle bus* between campuses’ (our italics) as they clearly understood that assisting students with autism to find their way around requires more than just providing transport. Assistance in travelling within the university, support when attending for interview, support for accessing learning centres and IT, extended submission deadlines, and a befriending scheme are all crucial aspects of support for many students with autism, as the provision of these supports by between 48 and 75% of respondents attests to; these may also be ‘quick wins’ for those establishments yet to provide them. Given that social difficulties are at the heart of autistic students’ university experience, we think that implementing a befriending scheme should be an especially high priority for the over 50% of establishments that did not report having such a scheme. One standout response to the befriending question referred to a ‘Socialeyes’[[18]](#footnote-18) programme to:

help participants explore the social world and become more confident in social situations … it does not tell learners how to change “inappropriate” social behaviour - but has been designed to help learners explore social interaction so that they can make an informed choice about how they might respond in similar situations; it aims to help learners develop their own social response repertoire.

The provision of support for potential students when attending for an interview would provide the university with an early opportunity to demonstrate its commitment to supporting students with autism and could be a contributory factor in the choice of university.

The contrast between establishments which clearly understood the importance of effective transitioning from school or college and those that appeared not to was marked.

Few universities could provide retention, graduation, and post-graduation status rates. We think it is important for all establishments to know how these rates for their students with autism compare to their ‘all students’ rates. This is particularly the case for post-graduation outcomes, given the need to support students with autism into employment.

We asked ourselves whether we felt that a university should have a specific policy relating to autism, or, if not, whether there was any need to make some specific provision for autism in a generic equality/disability policy. None of the responding establishments had apparently seen the need to do either. We concluded that an equalities policy confirming a university’s commitment to meet its statutory requirements should be adequate with one important exception. Such a policy would not include compliance with the non-statutory recommendation in the Ministerial Foreword to the ‘Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy’[[19]](#footnote-19). The Minister stated: ‘*We recommend that other providers of public services, such as providers of services to support people into employment … look to follow the guidance to help improve the delivery of the services they provide to adults with autism*: for example ensuring that staff who provide services to adults with autism have received autism awareness training would clearly be of value across *all public services*. This should lead to better outcomes for people with autism and make best use of public resources’ (our italics). Universities support people into employment and are covered by this recommendation. We concluded that a university equalities policy should include provision along the lines of the following example text (which also reflects our view that all universities should have a high-level autism working group reporting direct to their management board):

The University confirms its adherence to the recommendation in the Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy for other providers of services to follow the guidance to ensure that delivery of the services the University provides to its students with autism meet current good autism practice standards. A working group exercises oversight in this area and reports regularly to the University’s management board.

Although not all universities offering qualifications in autism responded to the survey, those that did appear to focus on their research and teaching as one would expect. However, given their presumed expertise in autism we think there could be a valuable wider staff development role for the teaching staff, perhaps in a ‘training the trainers’ capacity.

We analysed our data in three stages to identify any significant differences between the two data sets as first stage responders (disability support teams) were volunteers whereas second stage responders (FOI officers) were legally obliged to respond. Although there were no significant differences in terms of results, second stage responders often gave a better account of their institution’s situation than first stage responders, by providing more extensive data, providing unsolicited follow-up data, etc. This was the opposite of what we expected.

**Limitations**

We obtained responses from just over 60% (99 from c160) of the UK universities which, although a reasonable sample, still fails to account for a substantial number of establishments. For logistical reasons, only the online data (over half the 99 responses) was analysed by more than one team member; the other data was analysed by the lead researcher only. We would have asked additional questions but wanted to avoid respondents being able to rely on FOIA exceptions (although, in practice, very few respondents relied on these exceptions).

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1. Disability studies scholars generally prefer person-first language such as ‘individual with autism’. Adults on the autism spectrum usually prefer disability-first language such as ‘autistic individual’. So we use both. [↑](#footnote-ref-1)
2. <http://www.hesa.ac.uk/index.php/content/view/1973/239/>. HESA figures are based on student self-assessment. They may include students diagnosed and self-diagnosed with autism. Students are not obliged to report a disability so figures may not be fully representative of the total population of students with autism. [↑](#footnote-ref-2)
3. To ensure that the title of our study reflected the point made by the University of Cambridge that students with AS ‘are by definition very high achievers’, we eventually adopted the title ‘High Achievers’. [↑](#footnote-ref-3)
4. This study was undertaken by a group of independent scholars on an unfunded basis. [↑](#footnote-ref-4)
5. Section 8(1)(a) of the FOIA states that information provided in response to an FOI request must be: ‘in a form which, by reason of its having some permanency, is capable of being used for subsequent reference’. [↑](#footnote-ref-5)
6. For instance, one university provided figures for the years from 2010/11 to 2014/15 of between 19 and 25 but a figure of 59 for 2015/16. The latter figure could imply under-reporting in the earlier years. [↑](#footnote-ref-6)
7. Our like-for-like calculation is similar to retail groups which declare like-for-like differences in annual sales figures by deducting sales for shops opened over the period since the previous annual report. [↑](#footnote-ref-7)
8. A couple of respondents were in the midst of recruiting a full-time autism specialist. [↑](#footnote-ref-8)
9. Full-time coverage may be provided by a single member of staff or on a job sharing basis. Where a respondent had both full-time and part-time autism specialists we recorded them as a ‘full-time’ establishment. [↑](#footnote-ref-9)
10. One establishment recruiting their first autism specialist when responding to the survey kindly provided us with the person specification and job description for the new post. The person specification required education to degree level and ‘evidence of continuing professional development in the field of disability support with particular reference to Autism Spectrum conditions’ but did not require an autism-specific qualification. [↑](#footnote-ref-10)
11. We included mentoring schemes in addition to befriending schemes. [↑](#footnote-ref-11)
12. We included online prospectuses if there was a dedicated autism section, as well as those in hard copy form. [↑](#footnote-ref-12)
13. The response did not specify whether they recruited students *with a disability* to attend the Disability Working Group, as they simply wrote ‘students’, but we suspect that they recruit disabled students. [↑](#footnote-ref-13)
14. Autism is *not* a mental health issue, although it can lead to mental health issues. [↑](#footnote-ref-14)
15. One university provided data relating to degree divisions. In two out of the three years covered, the students with autism achieved a substantially higher rate of 1st or 2:1 degrees than was the case for ‘all students’. [↑](#footnote-ref-15)
16. https://www.gov.uk/check-a-university-is-officially-recognised/recognised-bodies [↑](#footnote-ref-16)
17. This establishment was unable to tell us how many students with autism they have. [↑](#footnote-ref-17)
18. The ‘Socialeyes’ programme covers: starting a conversation, eye contact, personal space, taking turns in a conversation, keeping on topic, talking about interests, sensitive topics, and ending a conversation. [↑](#footnote-ref-18)
19. https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/422338/autism-guidance.pdf [↑](#footnote-ref-19)