The ‘High Achievers’ project: an assessment of the support for students with autism attending UK universities

Nick Chown\textsuperscript{a}, Joanna Baker-Rogers\textsuperscript{b}, Liz Hughes\textsuperscript{c}, Kleio Nicola Cossburn\textsuperscript{d} and Pam Byrne\textsuperscript{e}

\textsuperscript{a}Independent scholar, Barcelona, Spain; \textsuperscript{b}Independent scholar, South Yorkshire, UK; \textsuperscript{c}Independent scholar, Lancashire, UK; \textsuperscript{d}Independent scholar, Staffordshire, UK; \textsuperscript{e}Independent scholar, Warwickshire

ABSTRACT
In the UK autism is classed as a disability under the Disability Discrimination Act 2005. Under the Special Educational Needs and Disability Act 2001, higher education 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 higher education. This was followed up with Freedom of Information Act requests to establishments that did not respond to the survey. We report our findings based on responses from 99 universities out of approximately 160 establishments in total. As autistic university graduates are at a disadvantage when compared to their non-autistic peers in obtaining employment after graduation, we propose that all higher education 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 (American Psychiatric Association 2013; World Health Organization 1992). Many individuals with autism\textsuperscript{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 UK 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 institutions (HEIs) 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). According to the Cambridge Asperger Syndrome Student Project, students with 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, 4). The percentage of students with autism is increasing year on year. The Higher Education Statistical Agency (HESA) recorded a rise of 77% in the number of students identified as having autism in UK universities in the three years to 2010/11. 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 experienced by those with autism, the National Audit Office (2009, 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). There have been few studies directly examining the needs of autistic students in post-secondary education by established researchers (Beardon, Martin, and Woolsey 2009; Gelbar, Smith, and Reichow 2014; VanBergeijk, Klin, and Volkmar 2008; Ying Cai and Richdale 2015), although in the last couple of years some valuable work has been undertaken, including a systematic review describing the experiences of and forms of support offered to individuals with autism in higher education (HE) in the UK and elsewhere (Gelbar, Smith, and Reichow 2014), a comparison of university experiences of nine students with AS in Spain and England (Casement, Carpio de los Pinos, and Forrester-Jones 2017), a comparison of student and staff perspectives on life at university for students with AS (Knott and Taylor, 2014), participatory action research into the lived experience of university life for seven autistic students in a North of England university (Vincent et al. 2016), and a summary of current forms of support for students with AS in US colleges (Barnhill 2016). The analysis undertaken by Knott and Taylor (2014) revealed some key differences between the perspectives of staff and students with autism on such important matters as impact of sensory sensitivities and disclosure of a diagnosis which require further investigation.

Van Hees, Moyson and Roeyers (2015, 1673–1674) 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’ survey of UK universities

We had just the one specific objective in mind for our survey: to better understand the current level of support for students with autism studying at UK universities. We wanted to understand the extent to which universities in the UK comply with disability discrimination law as regards students with autism through the provision of reasonable adjustments to reflect the specific needs associated with autism. Because our method – a questionnaire – did not allow us to link practice with outcomes, we were unable to confirm that practice identified through our survey represents best practice. However, the
specific areas investigated are based on current research, including the Cambridge Asperger Syndrome Student Project, and we have been able to highlight particular aspects of support for students with AS in some of these areas that we know from our experience in the field are likely to be of particular value. All aspects of our study were based on 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 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 to 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 the original questionnaire design, making minor changes to reflect feedback received. The question set used for both data collection phases is provided in the Appendix.

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.

How did we develop our question set? In some 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), e.g. the three training questions, the question about transitioning from school or college and the policy question. We wanted to be able to update the Cambridge report’s figures for students with AS in HE. Given the specialist knowledge required to support autistic students, we decided to investigate the extent of in-house autism specialist support
(and what establishments do in the absence of such support). We could not ask about as many aspects of support as we wanted to in order to avoid an overlong question set and the cost/staff time FOIA exemption. The choice of forms of support investigated was based on the work one of us undertook in an FE context (Chown and Beavan 2011), influenced by the personal and professional experiences of the team members. Feedback processes are ‘key’ aspects of the management process linked to organisational learning and continuous improvement in performance (Kaplan and Norton 1996). The questions on graduation rates, retention rates and percentages of students with autism transitioning into full-time employment, another HE course or training aimed to supplement data available from the Higher Education Statistics Agency. Finally, we provided space for freeform comments on matters not otherwise covered in the questionnaire.

Some of our questions required simple arithmetical/statistical analysis (e.g. adding up the number of students with autism, and calculating the percentages of establishments with and without autism specialists on staff). The bulk of the analysis work was qualitative in nature. Our approach to qualitative data analysis involved a three-stage process, as explained earlier: we first analysed the responses to the original survey questionnaire, then the FOIA request responses, and lastly the two sets of responses combined.

Data received via the online survey software was analysed by at least two members of the team to avoid individual bias. For logistical reasons, data received as documents was only analysed by the lead researcher. However, the lack of significant differences between the coding of the two or more researchers in relation to almost half the data received via the survey software gave us confidence in our overall analysis. All the qualitative data was of a fairly simple nature. Responses were read multiple times where necessary. In many cases we simply drew up lists (e.g. the qualifications held by university autism specialists). We coded themes as necessary as they were identified in the data (e.g. ‘compulsory training’ in the training-focused questions) and highlighted patterns in the data (e.g. the prevalence of ‘general’ equality and disability training rather than autism-specific training).

**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 a 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.

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 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-à-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.

How many students declared an autism spectrum diagnosis to the university during each of the previous five academic years?

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 exact10 (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 10 universities having more than 100 autistic students enrolled in 2014/15 and another 24 establishments having between 50 and 99 students in that same year.

Direct comparisons between the five academic years of interest to us (2010/11 and 2014/15) were not possible as the number of establishments reporting figures in these years varied substantially (from 47 to 84). However, the variation in number 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% (2045 to 3129) 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,11 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 number of students with autism in HE may have exceeded 200%. The actual number 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 it was 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 number of students involved would risk identifying individuals so that disclosure might breach data protection principles.

Do you have an autism expert/specialist on staff to provide your staff with advice on supporting students with autism (academically and pastorally)?

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). Forty (40%) of the respondent universities had no in-house autism expert/specialist12, 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 basis13, 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.
If you have in-house autism expertise/specialist support, please provide details of their qualifications and experience

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 its website showing its 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 Master’s 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 it had. In total, there appeared to be about 18 individuals qualified in autism across the 63 establishments employing in-house specialists. 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 with no mention of autism.

If you do not have an autism expert/specialist on staff, what arrangements do you make when you need access to specialist expertise in 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 (NAS), 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 than ourselves.’

What training and refresher training in autism do you provide for all new disability support staff and student mentors/other new non-teaching staff/new academic staff?

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 its 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 its 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 respondent 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 it had never been asked to provide training for its 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'. 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.

What form does support for students with autism take (12 support types were specified)?
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
number 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. We list the areas of support in percentage order (commencing with the highest).

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
four differences.

There was no consistency between the universities responding to our follow-up question regard-
inging the means used to obtain feedback on the effectiveness of the support provided for students
with autism. Virtually all the respondents answered this question. One university recruited a pool of
students\(^1\) who could attend its Disability Working Group chaired by a director. Another stated: ‘Our
Mental Health Coordinator\(^2\) will invite students to come and discuss any issues that might arise on a
regular basis.’ Other mechanisms included:

- feedback forms
- the National Student Survey
- individually-tailored disability support surveys
- discussion during mentoring sessions
- monthly reviews
- 1–2–1 sessions with students
- case reviews
- an online student feedback system

| Choices (respondents can tick as many of these as apply)                                                                 | No | %  |
|------------------------------------------------------------------------------------------------------------------------|----|----|
| 1. Students can 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 using 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\(^a\)                                                                                           | 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. A dedicated section in the prospectus outlining support available for persons with autism and who to contact for further information\(^b\) | 21 | 22 |

\(^a\)We included mentoring schemes in addition to befriending schemes.
\(^b\)We included online prospectuses if there was a dedicated autism section, as well as those in hard copy form.
• an automated email campaign
• a suggestion box
• interviews with 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)
• verbal feedback through support workers

How do you obtain feedback on the effectiveness of the support you provide for students?
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.’ Other establishments listed a variety of ways and means of adjusting support provision based on feedback received. 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 its Disability Working Group.

What arrangements do you make for new students on the autistic spectrum transitioning from school or college?
In response to the question asking about arrangements made for new students with autism transitioning from school or college, a significant number of establishments run 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 from school (although there was a great deal of variation between responses). One response appeared totally 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.

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’, setting aside a quiet room, 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. Another 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 Settling-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’.

**What arrangements do you have for non-autistic students to raise their awareness of autism?**

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 all non-autistic students. A leading autism specialist advises that autism awareness training should be delivered to students acting as a ‘buddy’ for a student with autism (Breakey 2006).

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 the university delivering 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. Another respondent wrote: ‘Most [autistic students] do not want their autism discussed or highlighted to fellow students.’ In some cases, awareness arrangements were targeted at classmates or flatmates of autistic students living in halls of residence. Forty-three establishments either had no provision at all or responded ‘available on request’ or similar.

Generally speaking, respondents that did attempt to raise awareness of autism amongst the student body often focused 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 (some linked to World Autism Awareness Day)
- awareness training for student mentors
- buddy arrangements between an autistic student and a non-autistic student sharing accommodation
- publishing information on autism on the university website
- information leaflets
- 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.

**Do you have a specific university policy relating to autism?**

Only one respondent stated that it 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 it had a policy on autism, it became apparent that it was referring to a section regarding support available for students with autism on its website, and that this was not an official university policy. We reviewed the relevant policies for the establishments that 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 had made provision specific to autism in its generic equality/disability policy.

**Please provide the graduation rate for students with an autism spectrum diagnosis and the graduation rate across all your students**

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 degree17, 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 that should be collecting this data actually are collecting it.

Please provide the retention rate for students with an autism spectrum diagnosis and the retention rate across all your students

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 that 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).

What percentage of students with an autism spectrum diagnosis go on to full-time employment, education or training?

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 number 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 number of students involved is 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 that, after advising that it does not hold this information, added that it ‘work[s] with students 1:1 either as case managers or mentors to help them manage the transition to post University life’.
If you offer qualifications in autism, do those teaching these qualifications play any role in raising awareness and understanding of autism across the university?

We asked those universities that 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 offered 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 it did not involve its autism teaching staff in a wider role at present, it 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’. A university with a leading autism research centre simply referred us to its ‘ground-breaking scientific research’ in autism.

Is there anything else you would like to add?

In response to the final question asking universities 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 Asperger’s to help them with this transition.

We conclude with an honourable mention for the respondent university that stated it was seeking accreditation under the NAS quality assurance programme. We found no university in the list of approximately 480 accredited organisations on the NAS website.

Discussion

How many students declared an autism spectrum diagnosis to the university during each of the previous five academic years?

It is difficult to estimate the total number of students with autism at university in the UK. We suspect that a figure of 5000 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, there may be as many as 9000 students with autism in total in UK HE, many of whom are high achievers (Hastwell et al. 2013). The World Health Organization estimates that one child in 160 has
but acknowledges that estimates vary substantially and some reported rates are much higher. The NAS considers that one in 100 people in the UK has autism (Brugha et al. 2012). Some studies have reported an even higher prevalence. Our estimate of 9000 students with autism in UK HE represents about one in every 250 students. Clearly, some autistic students do not disclose their diagnosis and others have yet to receive a diagnosis so this is likely to be a significant underestimate of the actual number of students with autism in UK universities. We suspect that the actual percentage of students with autism will still be significantly less than it would be if there were no barriers to entry to university.

Do you have an autism expert/specialist on staff to provide your staff with advice on supporting students with autism (academically and pastorally)?

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 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 NAS – and, clearly, considerable scope for other establishments and individuals to follow the lead of those who have in-house autism-qualified autism specialists.

What form does support for students with autism take?

Of the forms of support 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, let alone navigating campus-based establishments with many buildings (which may vary in layout) so the ‘inter-campus bus service’ response from one university, and the ‘we are a single campus university’ response from another, rather missed the point. It should not be difficult to provide assistance in getting from one lecture venue to another, especially during the first few weeks (e.g. through a ‘buddy’ arrangement). These responses stand in direct contrast to the university that referred to ‘helping a student to use the shuttle bus between campuses’ (our italics) as it 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’ 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.

**What arrangements do you make for new students on the autism spectrum transitioning from school or college?**

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

**Retention, graduation, and post-graduation rates**

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.

**Do you have a specific university policy relating to autism?**

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’. 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.

**If you offer qualifications in autism, do those teaching these qualifications play any role in raising awareness and understanding of autism across the university?**

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 because 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.
Final comments

Few studies conducted by established researchers have directly examined the needs of autistic students in post-secondary education, although in the last three or four years some valuable work has been undertaken and we confidently expect the situation to continue to improve. Although the number of students with autism at university is relatively small, it is nonetheless significant, increasing rapidly, but of little relevance to each individual autistic student charting a course through their HE studies as best they can. There is a substantial volume of advice and guidance for universities on how to accommodate students with autism, not least the findings of the Cambridge Asperger Syndrome Student Project. Our findings show that five of twelve ‘key’ supports were implemented by 75% or more of our respondents. Although there are no earlier figures with which to compare this, we think that it demonstrates some good progress over recent years. However, the implementation rates for the other seven supports varied from 22% to 72%, four being implemented by fewer than half the respondents. Whilst we accept that not all universities will be able to implement all 12 supports (see Table 1 for a list of these forms of support), these figures give a good indication of just how much more progress needs to be made to ensure that autistic students receive the support they need at university. All HE establishments are legally obliged to make ‘reasonable adjustments’ for students with autism so we have to conclude that most HE institutions are in breach of current UK disability discrimination law. They are also failing to adequately support many of their potentially high achieving students, which is neither good for the students nor for them.

Limitations

We obtained responses from just over 60% (99 from approximately 160) 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 (slightly over half the 99 responses) was analysed by two or more team members, the other data being analysed by the lead researcher only. However, the lack of significant differences between the coding of the two or more researchers in relation to almost half the data gave us confidence in our overall analysis. We would have asked additional questions but wanted to avoid respondents being able to rely on FOIA exceptions. However, in practice, very few respondents relied on these exceptions and it seems we may have underestimated the number of questions we could ask. In this first unfunded phase of the High Achievers project we were unable to seek the ‘autistic voice’ from university students with autism but hope to do so in a later, funded, phase.

Notes

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.
2. 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.
3. In this ground-breaking study under the auspices of the Stratus Writers Project the seven autistic participants not only collected the data themselves but also analysed it thereby ‘offering rich and potentially overlooked theoretical knowledge’ (Vincent et al. 2016, 1).
4. We hope to undertake a second phase of ‘High Achievers’ research that will seek the views of both students and staff on support provided for those with AS at university, looking closely at areas where there are significant differences of opinion between students and staff.
5. 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’.
6. This study was undertaken by a group of independent scholars on an unfunded basis.
7. We wanted the facility to compare the original questionnaire data with the FOIA response data despite the question sets being the same. This was because we wrongly anticipated a tendency for FOIA responses to be a bare minimum to meet the legal requirement, and therefore that such responses might not always be as thorough as responses
to the original questionnaire, which was more clearly a piece of academic research. As there was no noticeable
difference between the quality of the two data sets, we combined them for reporting purposes.
8. An FOIA request can be refused if ‘it would cost too much or take too much staff time to deal with the request’ (https://ico.org.uk/for-organisations/guide-to-freedom-of-information/refusing-a-request/).
9. 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’.
10. 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.
11. 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.
12. A couple of respondents were in the midst of recruiting a full-time autism specialist.
13. 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.
14. One establishment recruiting its 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.
15. The response did not specify whether it recruited students with a disability to attend the Disability Working Group, as it simply wrote ‘students’, but we suspect that it recruited disabled students.
16. Autism is not a mental health issue, although it can lead to mental health issues.
17. 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 first or 2:1 degrees than was the case for ‘all students’.
18. www.gov.uk/check-a-university-is-officially-recognised/recognised-bodies
19. www.who.int/features/qa/85/en/
20. This establishment was unable to tell us how many students with autism it has.
21. By the term ‘quick win’ in this context we refer to aspects of good autism practice which a university may be able to implement reasonably quickly and without incurring significant expense.
22. One of us led a research contract for a college of further education for six months and still experienced difficulty navigating its campus at the end of the contract.
23. 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.
24. www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

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Disclosure statement

No potential conflict of interest was reported by the authors.

Notes on contributors

Nick Chown is an independent autism advocate, mentor, researcher and trainer. He has undertaken research on barriers to learning for students with autism in further education, autism awareness in the UK police service, viva protocols for doctoral students with autism and diagnostic pathways for autistic adults. His doctoral thesis focused on language methods and the acceptability of Wittgenstein’s language game concept in autism. He is a member of the editorial board of the Journal of Autism and Developmental Disorders, and a reviewer for various journals. In addition to leading the High Achievers project, Nick is engaged with a university project mentoring autistic adults. His book on autism theory has been published recently.

Joanna Baker-Rogers is an independent autism researcher who also teaches in higher education. Joanna’s interest in the world of autism stems from the diagnosis of her son with Asperger syndrome. In 2006 she graduated from Sheffield Hallam University with an MA in the Education of Children and Young People with Autism. She is currently writing the thesis for her doctorate on the meaning of sociality and friendship for persons with autism. Her interests in the field of autism include:
social barriers, special educational needs, the lived experience of persons with autism, and the phenomenon of friendship and autistic sociability. Joanna is a founder-member of the High Achievers research team.

Liz Hughes is a former civil servant and IT systems designer/analyst who has a child with Asperger syndrome. She has an academic background in economics at degree and postgraduate levels but more recently has studied autism and gained various qualifications including a Postgraduate Certificate in Asperger Syndrome. She is a school governor with particular interests in special educational needs and autism. Liz advocates for and supports individuals with autism, and runs an online support group for people who live with autism and hypermobility. She is a founder member of the High Achievers autism research group.

Kleio Nicola Cossburn is a former police officer and parent of two children with autism. She has a Bachelor of Science degree, and a Postgraduate Certificate in Autism and Asperger Syndrome. Kleio is currently developing her research skills prior to undertaking doctoral studies. Her particular interests in the field of autism concern operational policing, and autistic service user involvement in professional training. Kleio is a founder member of the High Achievers research team.

Pam Byrne advocates for, and supports students with autism within a college of Further Education in England. With a postgraduate certificate in Autism and Asperger Syndrome, and a particular interest in special educational needs, the author is committed to enabling students to reach their full potential. In addition to experience of supporting students within further and higher education, the author is also works with a community interest company, supporting adults with autism and learning differences in work based activities, and providing opportunities to develop work, life and social skills.

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The High Achievers Survey Questionnaire

1. Please state the name of your university here (we are only asking this so we do not 'chase' any university unnecessarily). All data in our reporting and other publications will be anonymised.

2. How many students declared an autism spectrum diagnosis to the university during each of the previous five academic years?

3. Do you have an autism expert/specialist on staff to provide your staff with advice on supporting students with autism (academically and pastorally)?
   - Answer choices:
     - We have no in-house expert/specialist
     - We have one in-house expert/specialist
     - We have more than one in-house expert/specialist

4. If you have in-house autism expertise/specialist support, is this full time or part time?
   - Answer choices:
     - Full time
     - Part time

5. If you have part-time in-house autism expertise/specialist support, how many hours a week are worked?

6. What form does support for students with autism take? Please tick the box next to each type of support that you provide.
   (a) Support for applicants with autism when attending for interview?
   (b) Is there a dedicated section in the prospectus outlining support available for persons with autism and who to contact for further information?
   (c) Preference for halls of residence (if requested)
   (d) Can students stay in halls for the duration of their study?
   (e) Extra face-to-face tutorial time and/or email contact time with tutors/mentors?
   (f) Extended submission deadlines
   (g) Provision of scribes and/or audio-recordings of lectures
   (h) 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
   (i) Arrangements to ensure continuity of tutors between years as far as possible
   (j) Assistance in travelling to and from different locations in the university
   (k) Befriending scheme
   (l) Support in using access learning centres and IT

7. How do you obtain feedback on the effectiveness of the support you provide for students?

8. How do you act on feedback to ensure that support continually evolves and meets the needs of the students?

9. If you have in-house autism expertise/specialist support, please provide details of their qualifications and experience.

10. If you do not have an autism expert/specialist on staff, what arrangements do you make when you need access to specialist expertise in autism?

11. What training and refresher training in autism do you provide for all new disability support staff and student mentors?

12. What training and refresher training in autism do you provide for all new academic staff?

13. What training and refresher training in autism do you provide for all new non-teaching staff other than disability support staff?

14. What arrangements do you make for new students on the autism spectrum transitioning from school?

15. What arrangements do you have for non-autistic students to raise their awareness of autism?

16. Do you have a specific university policy relating to autism? (If you have such a policy, please email a link to it on your website or a copy of the policy to: npchownsurveys@gmail.com)

17. If you do not have a specific university policy relating to autism, does the university’s disability policy include any specific conditions relating to autism? (If there are such conditions please email a link to the policy on your website or a copy of the policy to: npchownsurveys@gmail.com).
18. If you know what your graduation rate for students with an autism spectrum diagnosis is please provide the following:
   (a) the graduation rate for students with an autism spectrum diagnosis
   (b) the graduation rate across all your students
19. If you know what your retention rate for students with an autism spectrum diagnosis is please provide the following.
   (a) the retention rate for students with an autism spectrum diagnosis
   (b) the retention rate across all your students
20. What percentage of students with an autism spectrum diagnosis go on to full-time employment, education or training?
21. If you offer qualifications in autism, do those teaching these qualifications play any role in raising awareness and understanding of autism across the university?
22. Is there anything else you would like to add?