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Document Version

Peer reviewed version

Citation for published version (Harvard):

Tolikas, T & Perepa, P 2018, 'Perceptions of students with autism regarding higher education support services', *Journal of Inclusive Practice in Further and Higher Education (JIPFHE)*, vol. 10, no. 1, pp. 20-39.

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Perceptions of students with autism regarding higher education support services

Thomas Tolikas and Prithvi Perepa

ABSTRACT

There is an increase in the number of students with autism accessing higher education (HE). There is also emerging literature about good practice for supporting these students in the HE context. However, there is still very little information concerning which specific services students with autism want. This study addresses this gap by gathering the views regarding the support services of the students in one HE setting. Fifteen students participated in this study and completed a questionnaire to share their views. One of the most significant findings was that while students use only the services which they need, they appreciated having the option to access a variety of services when needed. According to the students, the most helpful services are considered to be the following: - personal mentoring, transitional services, mental health services and the support to complete their application for Disabled Students' Allowances (DSAs). Students identified disadvantages which included lack of communication among services as well as the limited staff awareness of autism. This is a small-scale study, but the evidence which emerges from it indicates the need for further research in the field.

Keywords: Autism, Student perceptions, Higher Education, Support Services

INTRODUCTION

Autism is a complex and diverse developmental disability which impacts the areas of communication, interaction, flexible thinking and sensory processing. It is estimated that approximately 1% of the population in the UK or nearly 700,000 people are on the autism spectrum (National Autism Society, 2017). With the increase in population there are debates around appropriate use of language, with some autistic individuals preferring 'identity first' language and the use of the phrase 'autism spectrum condition' to describe their diagnosis. However, this is not necessarily shared by everyone with autism, and the participants in this research mainly preferred 'people first' language and the use of 'autism spectrum disorder' (ASD) when discussing their diagnosis. As the main aim of this study was to provide students with a voice, we decided to use their preferred language and are therefore using people first language throughout this article and keeping 'ASD' in all direct quotations.

The increasing population has led to an interest in the education provided to students with autism in primary and secondary school settings, but similar interest is not present when it comes to the Higher Education (HE) context. As a result, until recently limited research has been conducted to examine

the experiences and the needs of these students, and which support services can effectively meet their needs (Kerr et al., 2003). Powell (2003) noted that the lack of research might be the result of the widespread (but mistaken) assumption that autism is likely to prohibit individuals to study at this level. This might be the view held before 2003, however autism was included as an independent category of disability in the UK universities in 2003 (Higher Education Statistical Agency (HESA), 2015). Therefore, there are many universities in the country now which have a significant number of acknowledged students on the autism spectrum. The population of students with autism in British universities in 2003/04 was put at 165, whereas according to HESA (2015) the recent data shows this to be 2400. It is likely that the real population is even more since many students do not disclose their diagnosis or see the need to do so.

Access to a university does not automatically entail that they are able to reach their academic potential (Van Bergeijk et al., 2008). Low levels of attainment and employment were reported in the UK by Howlin et al., in 2004. This situation does not seem to have changed, as in a recent study by Equality Challenge Unit (2011) it was found that 24% of UK-domiciled graduates with autism were unemployed, which was the highest proportion amongst all disability categories. In addition, many students are unable to complete their studies due to problems such as excessive stress, high

dependence on families, and social isolation (Glennon 2001; Howlin et al., 2004; Van Bergeijk et al., 2008).

DIFFICULTIES WITH HE

There is an increasing awareness of the nature of autism and its implication for students while studying at a university. For example, transition from school to university, which can be difficult for most students, is particularly so for those with autism (Martin, 2008). While transition support systems are important, this is not the only area which impacts a student with autism. Beardon, Martin and Woolsey (2009) suggested that the difficulties which students with autism face could be grouped into four categories: social interaction, university social environment, course structure and curriculum requirements, and staff and peer understanding of the condition.

Students with autism often find it difficult to understand the instructions regarding how they should organise, plan and complete their assignment (Cai and Richdale, 2016). In addition, lack of staff and other students' awareness affects the socialisation and the communication of the students who are trying to change their behaviour to behave in accordance with the expected norms so that they can fit in at the university (Knott and Taylor, 2014; Vincent et al., 2016). In their research, Beardon and Edmonds (2007) found that students on the autism spectrum considered that their behaviour

is odd and disruptive. If this is their perception and they are trying to mask their autism, it could then impact on their self-esteem and mental health. The most difficult challenge for students with autism is to understand and respond to subtle communicative interactions (Vincent et al., 2016). Martin (2008) argues that the continuous effort that the students put in to fit the university social expectations can lead some of them to social exclusion, and in other cases impact their mental health and well-being. University staff might try and help the students, but Knott and Taylor (2014) found that while they are well-meaning they frequently lack a clear understanding of the support needs of students with autism, and therefore are unable to support them appropriately.

The nature of a university itself can make it difficult for some students to be part of the setting. In their study, Bearden and Edmonds (2007) found that students report sensory issues as a core stress factor. Other factors which can hinder the success of students with autism in a HE setting include sudden changes to timetables, having to talk in public, and assessment expectations such as having to make presentations for a module, all of which can increase the stress and anxiety (Van Hees, Moyson, and Roeyers, 2014; Fabri and Andrews, 2016). These challenges are common to every student studying at a university; however, as Liew et al. (2014) state, the difference is that while most students can adapt reasonably quickly and draw from the

support of their friends, for students with autism these challenges can rapidly lead to anxiety, depression, further isolation and eventually dropping out from the university. Research has shown that students with autism have the lowest graduation rates compared to students of other disabilities (Taylor and Seltzer, 2010). The causation for this could be multifactorial as discussed in this section.

SUPPORT SYSTEMS

The UK higher education providers are making reasonable adjustments in their academic settings to support disabled students, such as the provision of study mentors, extra time and provision of assistive technology. Although these academic adjustments could have benefits, there is also a danger that they could separate the students with autism from their peers and thereby increase their social anxiety and social isolation (Madriaga, 2010).

Most universities provide access to such support services based on whether the student has an official diagnosis and have access to funding (such as Disabled Students' Allowances (DSAs)). As Martin (2008) highlighted, the official diagnosis is the gateway to the services, but it is problematic since there are many students who do not have a medical diagnosis when they start their studies, or who fear the stigmatisation of the label and prefer not

to reveal it. Some students may also adhere to the neurodiversity movement and do not see the need to be diagnosed with a label. Another barrier to some of these services is the status of the student, as DSAs are not available for international students.

However, universities in the UK are trying to address some of the identified issues. For example, some universities provide students with an online toolkit to prepare them for the transition to university (Autism and Uni, 2017). The core themes of the toolkit cover: how to travel to campus locations, typical study situations, whom to disclose their autism to, as well as managing students' and parents' expectations regarding university. Some universities are also providing priority to disabled students for their accommodation and trying to make this suitable for their needs. Certain universities are using peer mentoring which Owen et al. (2016) found the students considered as beneficial in their studies. Adjustments are being made to assignment requirements such as providing extra time in exams or extension for completion of assignments (National Autistic Society, 2017).

While all these strategies appear to be moving in the right direction, there is very little evaluation of student perspectives regarding such services. This is the specific area which this study intended to address. We felt that knowing this information could help the universities and other support provider

organisations to become aware of what students deem to be a good practice to meet their needs.

RESEARCH METHODOLOGY

As the aim of this study was to explore the services provided for students with autism in a specific university and the perceptions of the students in this setting, a case study approach was used for this research. Cohen et al. (2011) state that case studies can provide an example of real situations which are experienced by people on a regular basis. The core limitation of this approach is that the findings lack generalisability. However, as Robson (2002) and Yin (2009) state, the purpose of a case study is not to achieve a statistical but an analytic generalisation, which fits with the aims of this research.

SAMPLE

Purposive sampling was used to select participants for this study. The criteria for inclusion was that they were studying at the university, had a diagnosis of autism, and were enrolled on the database of the university disability support team. We felt that if the student is registered with the disability support team, they are likely to be aware of most of the support services as well as accessing some of these. Letters for recruitment were

sent to all the students on the database which led to recruitment of fifteen students (8 females and 7 males) studying on the undergraduate and postgraduate programmes.

QUESTIONNAIRE

It is suggested that a good questionnaire should meet five criteria: a) clarity, b) reliability c) unambiguity, d) brevity, and e) communicability (Robson, 2002). This makes it an appropriate research tool to be used with the participants of this study as it combines the clear structure, sequence, and focuses on what is necessary, all of which are important for people with autism (Wing, 2002). Another significant advantage was that it provides the respondents with greater confidence because of their anonymity. We felt that this would enable the students to express their views without the fear that their answers might be disapproved of, or have an impact on their access to any of the University services. According to Cohen et al., (2011) an effective and attractive questionnaire should have a clear structure, clarity of wording and clear instructions. The questionnaire used in this study was organised in six parts using headings for each part regarding the content. In addition, clear instructions were provided for each section on how to complete the questions.

The research was conducted in accordance to the principles of the British Educational Research Association (BERA) 2011 and the University's ethical procedures. Participants were provided with an information letter which explained the purpose of the study and how the data would be sorted and used, as well as providing them with a right to withdraw.

RESULTS AND DISCUSSION

A thematic analysis was used for the qualitative data which was collected.

Themes were identified by using the constant comparison method, and then then cross checked between the two researchers. Descriptive statistics were used to analyse the quantitative data.

CONTEXTUAL INFORMATION

The university where this research took place has most of the student accommodation on campus. The disability student service is based along with all the other student services and holds regular drop-in sessions. For the last three years, this team along with other services has started providing a taster session for students with autism before they start at the university. Those who are registered with the service have access to accommodation adjustments and priority, disabled parking permits on campus, individual study skills support and a personal mentor. These latter two are only available to those with DSA funding. DSA is also used for

accessing specialist assistive technology. Students without DSA can access general study skills support which is available to all the students. The disability student service also provides information to staff regarding reasonable adjustments which a student may need, which are developed in consultation with the student. In addition to this team there is a mental health team which provides counselling services to all the students. Other than these university-led services, there is a students' union society for autism which provides peer support and regular events.

DEMOGRAPHIC DATA

A total of 15 students, who came from various faculties within the university, took part in this study. One of the postgraduate students was an international student and therefore did not receive DSAs. Further demographic data is provided in Table 1.

Table 1. Demographic data

| Demographic data | |
|-------------------------|--|
| Gender | 8 (53.3%) male |
| | 7 (46.7%) female |
| Level of study | 13 undergraduates (7 in final year, 2 in second year, 4 in first year) |

| | |
|---------------------------|--|
| | 2 postgraduate students (1 pursuing MA and 1 a PhD) |
| Age range | 18-22- eight students |
| | 22-35- seven students |
| Domicile status | 14 home or EU students |
| | 1 international |
| Official diagnosis | ASD along with anxiety and depression- 6 |
| | Asperger syndrome- 5 |
| | Autism-2 |
| | Autism and dyslexia- 2 |

AWARENESS OF THE SERVICES

All the students were aware of the services provided by the University with five (33.3%) students stating that they are very aware, six (40%) being aware and four (26.7%) quite aware. The service which a majority (six) of the students mentioned as being most aware was the University's disability support service. This was understandable as the students were registered with the service, which in addition has a dedicated page on the University website. The level of awareness about various other services differed among the group. Only eight students were aware of the students' union group for autism. This is significant, as literature recommends (Owen et al., 2016)

peer mentoring as good practice and many students in this study considered it would be useful or helpful to receive such support when they begin their studies. Some participants also felt that having information about other students who succeeded at the University would be useful. This can be seen from the following comment by one of the participants:

'I would encourage the use of students with ASD as case studies who have gone on to graduate, find employment, and have achieved at the university, and what barriers they overcame, so that new students who come can relate and not feel isolated when transitioning from leaving home and going to university.'

However, some indicated that they would like opportunities to interact with neurotypical students (those without autism) because only then could they be inclusive members of university. For example, one student said;

'I'm not really into hanging out exclusively with other people that have ASD.'

It seems then that while a peer mentoring scheme is considered to be a good idea by most, this view was not necessarily shared by everyone.

ACCESS TO SERVICES

Most of the students (93.3%) had no difficulty in accessing the University services. 46.7% (7 students) felt they were very easy to find, 26.7% (4) easy, and 20% (3) quite easy. They all considered the University disability support team as a key player in making other services accessible. As many students replied;

'Once arriving at the university, I first entered student services where the xxx team (name of the disability support team) is located, and I was directed to them very quickly.'

and

'I discovered xxx (disability support team) on the University website, who I emailed with minor concerns about what to do and how to do it. They then guided me through the process and helped me with any queries after helping me send off my DSA'.

Furthermore;

'I was invited on a day just for students with ASD. I found accessing information about the services the university provided very easy along with the staff who were kind, understanding and very helpful.'

These comments highlight the crucial role which disability support teams can play in universities to help students both in transition and in settling at the

university. However, not all students found the location of the service accessible as this student commented:

'When I was attending the university to visit and look around I could not find and it was not obvious or clear where the support was..... I would not say it was easy as I feel the support was hidden.'

This student's experience highlights the importance of making this information accessible not only on the website, but also during university open days and the induction process.

PERCEPTIONS ON MENTAL HEALTH SERVICES

With high levels of anxiety and depression in students with autism, mental health services are increasingly being identified as one of the most significant services in universities. In this study, 33.3% (5 students) of the sample reported that they did not have access to mental health services at the University. Most of these students chose not to use the service as they preferred to talk with their personal mentor and/or therapist. Out of the rest 66.7 % (10 students) of the sample, 20% (3 respondents) answered very satisfied, 33.3% (5 students) satisfied and 13.3% (2 participants) dissatisfied.

REASONS FOR SATISFACTION

The main reasons for satisfaction were the experience, knowledge and support of their mental health advisor. As a student commented:

'The lady was very supportive and understanding, helping me to understand my difficulties and find strategies'.

The students noted that they could not finish their studies without the support of mental health services because they struggled with anxiety and depression. This concurs with what Fabri and Andrews (2016) and Madriaga et al. (2008) found, that mental health issues such as anxiety can lead students to abandon their studies and that therefore support for students regarding their mental health issues is vital.

Participants commented on the multifunctional role that their mental health advisor played. As this student noted, her mental health advisor

'always responded quickly and helpfully to my emails and communicated with lecturers for me when I needed help or extensions on deadlines, as well as helping me sort out any other disability-related issues when needed'.

Another student reported *'I see a mental health adviser once a fortnight, and she is always able to support me when I am struggling – either in*

person or over the phone. She can think objectively about my issues and help me to see them from a different perspective'.

These responses show a trusting relationship between students and their mental health advisor which could help them to raise their self-confidence and reduce loneliness.

REASONS FOR DISSATISFACTION

The main reason that some students reported dissatisfaction with the services was because of the process to access the mental health services. Students reported that they felt uncomfortable going to student services to book an appointment because that would mean that other staff members in the university would be aware of their health issues. This mirrors what Davidson and Henderson (2010) found, that students with autism do not like to disclose and talk about their condition to everyone. This indicates that alternative options for making appointments should be provided, so that the students do not feel that they will be identified or stigmatised by other members of staff or their peers.

Another issue which the students in this research highlighted was the delay in getting an appointment, with the result that urgent mental health issues cannot be dealt with. One student also felt that the staff in the services lack

knowledge on how to support more complex mental health difficulties.

Beardon and Edmonds (2007) found similar results in their study regarding the knowledge of autism in mental health services. It appears then that the level of satisfaction that the students have with the mental health services is very much dependent on the level of knowledge that the staff have of autism in addition to their understanding of mental health conditions.

All the students, whether they were satisfied or dissatisfied with the service indicated that they would like the same mental health advisor throughout their studies at the university. This is understandable both because of the importance that routine and familiarity play for some individuals with autism, and because of the nature of the relationship which is based on mutual trust, and which can only be developed through regular interaction with the same person.

PERSONAL MENTOR

Students reported how important a personal mentor is for them, with 40% (6 students) reporting that such a person is very important for them, 33.3% (5) important, 6.7% (1) slightly important. However, the remaining 20% (3) believe that it is not important. Although most students agree on the importance of such support, there seems to be disparity in terms of access.

Ten of the students (66.7%) answered that the university provided them with a personal mentor while five (33.3%) participants did not access a personal mentor because they did not need one. This perhaps reflects in the levels of satisfaction mentioned above, as students who did not access the support also rated this support as less important.

REASONS WHY A PERSONAL MENTOR IS IMPORTANT

Every student who has a personal mentor reported the crucial role they play in academic and social situations. Students viewed their personal mentor as a person with whom they can discuss the difficulties which they are facing on a daily basis. As this student states;

'The mentor helped me to organise my workload, remain calm and gave me advice which helped me to improve the quality of my work. They made university life a lot easier.'

In addition to the personal mentor, the students appreciated having a personal academic tutor. As this student says;

'My personal tutor was also my lecturer on many occasions and was leading many of my regular workshops therefore once I disclosed to her that I was on the ASD it made the experience at university much more bearable.'

As mentioned above, having a familiar person makes life predictable and leads to developing trust. Students commented that these regular meetings provided them with a sense of routine which they appreciated. They also reported how their tutors were flexible to accommodate their needs, as this student reflects;

'I kept the same personal tutor throughout all three years at the university – he took me on for my dissertation despite my area not being an area he specialised in, because he knew the familiarity we had was significant for me. He worked hard to communicate with me in a way that I was comfortable and was available for regular visits.'

The evidence from this study suggests that having a consistent personal mentor or tutor could be vital for some students to succeed in their studies and to continue at the university. This is an important aspect for universities to consider for increasing retention of students with autism.

PERCEPTIONS ON TRANSITION AND ACCOMMODATION SERVICES

The participants in this study were requested to evaluate and provide their views regarding the following transitional services which the University offers: priority accommodation process; pre-arrival enrolment; bespoke

applicant visit; support to apply for DSAs; introduction to the team of specialist mentors; and 1:1 support to help with the orientation to the course during the first few weeks. It is noticeable that 80% of the students (12 students) reported that the transitional services cover their need while 20% (3 students) answered that they do not. However, even the students who reported satisfaction with the transitional services did not use all of them and only used those that they need. Some students mentioned that they were not aware of some of the services or that they did not exist when the students started at the University. This is understandable as special transition support was only being offered over the last three years. The age of the student seems to impact the need to access such services as can be seen from the following comment:

'I think due to my age (29) and having lived in a variety of places and faced many new experiences transition services, apart from help with applying for DSA were not really needed'.

Helpful transition services

Where students did access transition services they reported various aspects which they felt were helpful for them to start at the university. These included opportunities to see the accommodation before moving which helped to reduce anxiety, and staff being flexible to meet the students' needs. For example, this student says;

'The accommodation services allowed me to have a mini fridge in my room due to my mental health illnesses which was extremely helpful'.

In fact, none of the students who used the accommodation services reported any dissatisfaction with them.

However, only 53.3% (8 students) of the sample used university accommodation while 46.7% (7 students) did not, either because they commuted to the university from their home or they chose to live independently. These findings are similar to those of Beardon and Edmonds' (2007) and Madriaga et al.'s (2008) study, which found that 50% of their sample were either living alone or with their parents. This could be because of sensory and social demands in university accommodations which prevent students from accessing such accommodation (Hastwell et al., 2013).

NOT HELPFUL TRANSITION SERVICES

Although several students considered that the bespoke applicant services were not helpful, most of these students were not aware that this service existed. This highlights the importance of communicating about existing support to prospective students. Some students commented that this support was only developed since they started at the university. As mentioned in the contextual information, the university is continuously

working on improving its support services and the bespoke applicant service has been initiated only in the last three years.

Some students felt that the taster day for students with autism was not helpful for them because of the way autism affected them. As one student explains;

'However, the taster day felt very basic and more directed towards those with ASD students higher on the spectrum experiencing more severe symptoms with social and emotional needs. Therefore, I left the taster day earlier and proceeded to carry out the activities planned independently'.

It is possible that some students are not aware of the support that they need and therefore do not access the available services. Nevertheless, even students who did not access services in this study recognised that while such visits may not meet their needs this could be beneficial for some other students on the autism spectrum.

ACADEMIC ADJUSTMENTS

Extra time for examinations and having access to a separate exam room were the most used academic adjustments, with nine students saying they

have accessed these. Students also appreciated the sensitivity which was shown to meet some of their needs, as this student comments;

'I had extra time available if I needed it. After struggling with the exam hall, and then a smaller room with others in year 1, I was given a room by myself for the remainder of the time I was at the university. The room was always adapted to meet my sensory needs, which included facing away from windows or having them covered to reduce visual distractions'.

Students also provided examples of having the option to take exams on computers as another reasonable adjustment which was provided to them and on the whole appreciated the helpful staff.

The main reason for dissatisfaction with the support was around communication again. This student provides an example for this,

'I was given extra time, rest breaks, and a separate room due to my severe exam anxiety, however during the exam season my room numbers were often wrong, my invigilator was late or did not arrive, which in turn made the entire experience much more stressful'.

Some students reported that although reasonable adjustments were stated in their reports, these were not considered during the assessment process, while a minority stated that these options were not offered to them at any

point. Although only a small minority of students reported these negative experiences, it does highlight the importance of clear channels for communication, so the required information is shared with the students and staff, and measures are put in place to ensure that the promised adjustments are available for the students.

STAFF AWARENESS

Eight students (53.3%) were dissatisfied or quite satisfied with staff awareness of autism, while only 5 (33.3%) students replied satisfied. One student (6.7%) reported that it is not necessary for the staff to know about autism because he believes that they should treat students with the condition in the same way as others. One student (6.6%) mentioned that he was not sure about how much the staff understand autism. These findings mirror those of Beardon and Edmonds' (2007) research where 45% of students were not satisfied with the knowledge and consequently the support from university staff. Thus, this similarity between two studies reveals the on-going nature of this issue and the need for staff training programmes in autism.

CONCLUSION

The aim of this study was to explore whether the support services being provided in universities are meeting the needs of students with autism. This study confirms that most suggested strategies and services to support students in the literature are appreciated by the students. This research has highlighted the important role which mental health advisors can play in the success of a student with autism at the university along with other professionals such as a mentor or personal academic tutor who can all provide consistency and support for the student. The need for these professionals and other staff at a university to be knowledgeable about autism and have a positive attitude has also been raised by the students. The key factors for satisfaction with services has been identified as having trusting relationships with staff, and flexibility in meeting the needs of the individual. The results show that students only accessed services which they require, but that there is a need to have a wide range of services because of the diversity of requirements amongst individuals with autism. Students mentioned they would like more opportunities for social inclusion with options such as peer mentors helping them to navigate the university life.

However, these findings will need to be considered along with the limitations of this study. The sample size is rather small and includes self-selected participants. It is possible that only students who had a specific agenda took part in this research and therefore it is likely that having a bigger sample

could have led to a different set of findings. The sample included mainly undergraduate and home students. It is likely that the needs of students at postgraduate level and those who are coming from abroad might be different. In fact, transition for an international student with autism could be even more challenging. These aspects certainly need further exploration to develop accessible services for all students on the autism spectrum.

In spite of these limitations, this research does draw attention to some key aspects which universities need to work on, such as having clear communication systems which help the students to be aware of the services they are entitled to and enable them to access these when required. The study adds to the plea from previous studies regarding the importance of training staff in HE settings in autism to avoid some of the negative experiences which students in this study have experienced. Developing peer mentor schemes which involve students with autism as well as neurotypical mentors will also enhance the chances for these students to be included in the academic and social context.

ACKNOWLEDGEMENTS

We would like to thank all the students who shared their experiences with us about accessing services.

DECLARATION OF INTEREST

This project has not been funded by any research body.

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