



# **Perceived Barriers and Challenges to Autistic Students in Higher Education**

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## **Abstract**

Autistic students in higher education face more barriers than those who are non-autistic (Dillenburger, McKerr, Jordan & Keenan, 2016) due to stigma and misconceptions held by the public (Zerbo, Massolo, Qian & Croen, 2015) and the ineffective supports in place (Ward & Webster, 2017). These difficulties may also overlap with difficulties faced by autistic people in other areas of life due to having autism-specific difficulties. Universities are particularly difficult for autistic people to access, with adaptations in higher education often overlooked (Lambe et al., 2018). To find out what sort of barriers people are aware of in higher education, 11 staff and students were invited to take part in focus groups to discuss what they saw as key barriers to autistic students in higher education. Thematic analysis revealed six key themes that showed areas in which staff and students perceived significant barriers to higher education. Results show that the difficulties perceived overlap with existing known difficulties in areas such as accessing healthcare and primary and secondary education. This research is not generalisable to large populations due to the limited sample size and purely qualitative approach however it does highlight key issues that are perceived as barriers to higher education for autistic students, and could form the basis of research conducting further investigation, or looking to trial improvements aimed at tackling barriers to access of higher education.

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## **INTRODUCTION**

Autism Spectrum Conditions (ASC, from here on referred to just as autism) are characterised in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) by social, communication and behavioural difficulties, restrictive repetitive behaviours and excessive fixed interests, that become apparent in early childhood and persist across the lifespan [5th ed.; DSM-5; American Psychiatric Association (APA), 2013]. This can lead to difficulties in daily life including a higher predisposition to developing co-occurring mental health conditions such as mood or anxiety disorders (Shochet et al., 2016). Other difficulties can include sensory sensitivities (Talay-Ongan & Wood, 2000) that can be affected by the environments the autistic person is in and the stress levels they are under (Corbett, Schupp, Levine & Mendoza, 2009). Challenges caused by autism, and by services that are not adapted to catering for autistic people's needs result in difficulty accessing services such as healthcare (Warner, Parr & Cusack, 2019), and education (Goodall, 2018) and these struggles accessing services may also include higher education (Cage & Howes, 2020). These difficulties manifest themselves differently in every autistic person, and so due to the heterogeneity of the neurotype, which can make the creation of accessible environments and services incredibly difficult.

Although it has been proposed since the turn of the century, that autism is not necessarily a disability and that difference would be an accurate term to use (Baron-Cohen, 2000), we are now only considering autism as a differing neurotype. Research is starting to recognise the neurodiversity theory of autism rather than the disability theory of autism, and that autism is a natural human variation (Jaarsma & Welin, 2011).

Autism as a neurotype is a popular explanation amongst an emerging autistic culture that share the views that the autistic person is not to blame for their neurotype, nor should society stigmatise or label them as disabled because of it (Jaarsma & Welin, 2011). It is argued that an early inclusion policy in schools could help normalise neurodiversity, lead to better practices and have better outcomes (Mackenzie, Cologon & Fenech, 2016). This could show that with greater inclusion and acceptance of autism, outcomes could be both better for those who come into contact with autistic people and the autistic people themselves.

Autistic people find themselves struggling to access a wide variety of services such as the aforementioned healthcare and education, and they can also struggle securing employment (Sarett, 2017). This can be due to other difficulties such as the fear of disclosing their diagnoses (Mary Rose, Burke, Quinn & Harris, 2019; Sarett, 2017), and those who are providing care or employment or education being uninformed about autism (Gurbuzz, Hanley & Riby, 2018; John, Knott & Harvey, 2017) which tend to make their access to a range of services incredibly difficult. While research has been done into the accessibility of healthcare and education services, and the accessibility of employment for autistic people, the accessibility of universities has been largely understudied, and thus warrants further exploration. Expanding on this field with an exploratory study may lay groundwork for much more comprehensive and detailed quantitative studies, which could in turn lead to changes made in higher education to make them more accessible to not only autistic students, but students with disabilities who would also benefit from these changes.

Research into the perceived barriers to autistic students in higher education is an emerging, promising field of research. Despite there being few studies published in this area there is a basis using this literature and literature investigating accessibility of other services to autistic people, to form an exploratory qualitative study into the experiences of staff and students in higher education. Previous literature primarily looks into either the educational support provided for autistic students as for instance stress management regarding assignments and navigating group work, which in turn could help reduce anxiety and feelings of loneliness (Hillier et al., 2017). Further research shows that individualised support for autistic students could be very beneficial in helping to navigate the challenges of a university environment (Thompson, Bölte, Falkmer & Girdler, 2018), or transition to university (Lambe et al., 2018; Lei, Calley, Brosnan, Ashwin & Russell, 2018) as transition for autistic people has been shown to be a challenge. For many autistic people, these challenges come in the form of changes to routine (REF) and new social situations (REF)

However existing literature only covers one single group perspectives of student life, looking at the perspectives of all staff, or focusing on an all student perspective, rather than showing what the overall perceived barriers to autistic students are amongst teaching staff, support staff and autistic students themselves. This is important as we could examine

differences or similarities in opinion, which could inform the development of training programmes or strategies used to inform staff and/or students.

This study could also help to the perceived struggles of autistic students in higher education, and exploring the perceived struggles could provide insight into autism awareness and understanding in amongst staff and students. What this research finds may overlap with existing literature about the accessibility of other services such as physical and mental healthcare, primary and secondary education, and employment, or it could show a set of challenges and struggles unique to higher education amongst those in the study, which could then be used as a basis for future research.

#### LITERATURE REVIEW:

Disabilities make most services and places much more difficult to access, universities being particularly so as many of them are older institutions that were not built to be particularly accessible for those with differing needs and supports, and universities offering differing support depending on medical diagnosis (Järkestig Berggren, Rowan, Bergbäck & Blomberg, 2016). Students with disabilities often also opt not to tell their institutions of their disabilities for reasons yet unclear, but universities need to be aware that they should be catering for an invisible population who have needs of support and changes to curriculum design in order to meet their learning challenges (Grimes, Southgate, Scevak & Buchanan, 2018).

University can be difficult to access for those in a wheelchair, or for those who are hard of hearing or partially sighted, as the settings are not set up in suitable ways (Butler, Holloway, Marriott & Goncu, 2016; Riddell et al., 2006; Madriaga et al., 2010) and interventions, while some of them are effective such as allowing disabled students extra time in exams (Holzer, Madaus, Bray & Kehle, 2009), there are still greater difficulties accessing the same opportunities as a non-disabled population (Riddell et al., 2006). Effective supports and interventions have been studied and somewhat implemented for some physical disabilities, however 'invisible' disabilities such as developmental disorders are much less studied and supported in a higher education setting (Mullins & Preyde, 2013)

Autism is classified as an invisible disability, with awareness of it in a university setting limited (Tipton & Blacher, 2013). This could potentially lead to little or no support for autistic students within a university setting, or the implementation of ineffective supports due to a lack of awareness. Autistic people also have specific needs that other disabled students in the university may not need, for example while a physically disabled student may require all buildings and rooms to be ramp accessible, autistic students may need facilities such as a quiet room, or further academic support and sensory adjustments to their environments (South & Rodgers, 2017). Autistic people may also be more susceptible to bullying in a university setting compared to students with visible disabilities, and find that they have to explain themselves and their autism to their peers to stand a chance to fit in (DeNigris et al., 2017). A visible disability such as a person in a wheelchair may also be subject to bullying, but also greater empathy about their condition as it is a visible condition. Autistic students need to actively explain their autism to neurotypically developing people to gain some of the same empathy and understanding for their disability, and to identify themselves as having differences from their peers.

#### Difficulty accessing education

Access to education even in primary and secondary school can be a challenge to autistic people, and by examining this a basis of knowledge could be formed as to potential challenges that autistic people could encounter in university. Perceived barriers could reveal an overlap between challenges faced in primary and secondary education that we also see in universities, or it could reveal a type of educational challenge unique to universities such as difficulties the change in lifestyle and routines bring.

Autistic students have found bullying to be a significant problem throughout their education (Hebron, Oldfield & Humphrey, 2016), which is more likely to lead to school truancy (Havik, Bru & Ertesvåg, 2015) suggesting that bullying from peers could make education inaccessible. While there are reports of less chronic bullying within a university setting there is evidence to suggest that this still happens, with those being bullied more likely to identify as autistic to explain themselves to their bullies (DeNigris et al., 2017). This suggests identifying as autistic may help explain some of the more visible traits and communication difficulties that come with autism, however it shows that higher education is still a setting in

which autistic students could struggle accessing. Based on previous literature showing bullying leads to school truancy it would not be unreasonable to suggest that bullying in a university setting may also lead to truancy, which would be an interesting avenue to explore within this research.

Staff teaching in public schools reportedly have higher levels of burnout, due to a lack of understanding of autism and an understanding of the different needs the autistic children in their class could have compared to their typically developing peers (Boujut, Dean, Grouselle & Cappe, 2016). A lack of autism awareness training has detrimental impacts on those working with autistic people and the autistic people themselves; with concerns about how lack of staff training would affect the overall quality of the service they are provided (Dillenburger, McKerr, Jordan & Keenan, 2016). This has not been examined in a university setting, so more research is needed to examine whether autism awareness can impact on university faculty's ability to carry out their roles and provide the supports and assistance autistic people need. To spread more information to the public about autism, broadcasting the information people need to know has been suggested, as well as including the information in online media content (Mitchell & Locke, 2014). However, the feasibility of this would need to be examined, alongside the benefits and effectiveness of training courses that are developed to promote autism awareness. The autism community support the idea of more research to help them in areas of day-to-day life such as reducing stigma and heightened public awareness and understanding, despite research funding for autism not being prioritised in this area (Pellicano, Dinsmore & Charman, 2014). It is unclear as to whether these methods would be an effective way of reducing the stigma surrounding being autistic, but more autistic people see this as a strategy to be used to help improve the visibility of autism and the heterogeneity of the neurotype. It would be interesting to see whether support and teaching staff and autistic students setting share the same views.

While recent literature is challenging the gender bias in autism, with things like male centric diagnostic criteria being challenged to properly be able to identify autism in women, it is thought that the gender ratio is a lot narrower than the original 4 males for every one female with autism (Suckle, 2020). Despite this, and because it is still a new field of literature, autism is still viewed as a predominantly male condition, especially by schoolteachers (Whitlock, Fulton, Lai, Pellicano & Mandy, 2020). Access to schooling for



autistic girls may be difficult, as teacher may miss the struggles autistic girls can have, or think them to be something else (Whitlock, Fulton, Lai, Pellicano & Mandy, 2020). While portrayal of autistic women in the media is increasing, women on the spectrum are often underrepresented, particularly in the media. However, the representation of autistic girls and women in the media is slowly increasing with the tendency to portray them as high functioning. These portrayals, however, are not without their share of myths and autism stereotypes (Tharian et al., 2019). It is not necessarily clear the impact this is having on awareness of autistic women in education, something which could also be reviewed in a university setting to see if these issues persist.

Executive functioning difficulties could make education increasingly difficult, as the autistic person could have trouble keeping themselves organised. This could lead to difficulties handing homework in on time, managing their time and notes, and turning up to lessons with the right equipment (Ryan & Marshall, 2018). Poor executive functioning can also have a detrimental effect on a child's social life in school leading to more playground isolation and less interaction with other children. Working memory and planning and organisation are shown to be key to social functioning, as well as succeeding in education, and if executive function skills are not taught, primary and secondary education at a mainstream level could seem inaccessible to autistic children and their families (Freeman, Locke, Rotheram-Fuller & Mandell, 2017). If insufficient organisational support is offered, this could not only limit an autistic person's access to primary and secondary education, but university and other services as well, leading to barriers across all areas of life throughout the lifespan, as executive functioning difficulties are shown to be sensitive to age related cognitive decline (Geurts, Pol, Lobbestael & Simons, 2020).

#### Difficulty accessing healthcare

University students tend to suffer from poorer standards of health due to factors like a poorer diet, as well as increased mental health problems due to anxiety and depression (Grasdalsmoen, Eriksen, Lønning & Sivertsen, 2020). Autistic students could be even more vulnerable to these types of difficulties due to often having already restricted diets which can lead to health issues (Folta et al., 2020), and a susceptibility to anxiety disorders

(Cleinmark et al., 2020) which could in turn impact on health and the requirement to seek help from healthcare services for physical or mental health issues.

Struggles accessing healthcare have shown to be common for autistic adults, which could stem from their difficulties being able to ask for help, instead often opting to do most things themselves even if they would fare better with support (Dymond, Meadan & Pickens, 2017). This could also create difficulties accessing other services such as employment services, any support offered in primary and secondary school education, and could overlap with barriers in higher education for autistic students. In universities this could potentially lead to autistic students having the difficulty taking the first step to accessing any support available. Despite there being a few strategies developed to help autistic children feel more confident and comfortable asking for help (Gillespie et al., 2017). it is unclear as to whether these would be effective in a higher education setting, or whether autistic students still face the same difficulties in asking for help.

Autistic people can struggle asking for help, or even recognising that they need help until they are at breaking point, particularly when it comes to accessing mental health support. They are also deterred from accessing support due to a fear of not being believed or listened to, due to difficulties communicating their emotions (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018). Long waiting lists can also act as a barrier or even a deterrent to autistic people seeking psychical or mental health help (Crane, Adams, Harper, Welch & Pellicano, 2018).

Autistic adults feel that there are limited support systems in place that can help them with a broad variety of issues that those who are not autistic can access without issue. Mental health issues, suicidal thoughts and behaviours and self injury have been highlighted as key issues that autistic adults struggle to get help with. This is due to inaccessibility, lack of physician knowledge of autism and the lack of appropriate treatment for autistic people with mental health difficulties (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018).

Mental health support seems to be inaccessible to the majority of young autistic adults in the UK. Autistic people across the UK have described that it is difficult to evaluate their own mental health, they experience a lot of stigma and have reported facing severe obstacles

when trying to access support for mental health. Autistic people have said that people listening to their requirements and learning from them is crucial to meeting their mental health needs (Crane, Adams, Harper, Welch & Pellicano, 2018).

Healthcare is a service autistic adults struggle accessing within the UK, and research shows that autistic people who have health problems often have greater trouble accessing healthcare experiencing significantly more barriers to using the service than those who did not. Autistic patients with complex health problems often reported dissatisfaction with the service and the quality of their care much more than those that did not, and a lack of adequate healthcare could cause distress to autistic people if it does not meet their needs (Vogan, Lake, Tint, Weiss & Lunskey, 2017). Key barriers autistic people face when trying to access healthcare are shown to be patient-provider communication, sensory sensitivities, planning issues and executive functioning issues, (Mason et al., 2019), showing executive functioning difficulties can create barriers to accessing a large variety of services, and could potentially also affect university access.

Sensory sensitivities can be a key factor in whether a support is accessible or not to autistic people, which can contribute to anxiety. Anxiety problems when faced with the prospect of going into an environment that makes an autistic person uncomfortable or distressed can greatly decrease the chance of them choosing to get support and care (South & Rodgers, 2017). Anxiety and depression are already recognised as commonly co-occurring conditions in autism (Hollocks, Lerh, Magiati, Meiser-Stedman & Brugha, 2018) and so stressors like sensory sensitivities can make these more likely or severe. If their GP has a waiting room that causes sensory overload for the autistic person, they would be less likely to seek out healthcare when they encounter a problem with their general health.

It is acknowledged that a wide variety of factors including sensory needs, communication difficulties, other social difficulties such as asking for help, and misunderstandings surrounding autism, can all create barriers for accessing healthcare (Kim, 2014). These are difficulties that are known to research, that autistic people can struggle with, and so these difficulties may overlap with a university setting and the barriers to accessing higher education may be barriers based on these difficulties.

#### Difficulty accessing employment

Reasonable adjustments are crucial for autistic people to be able to access a wide range of services such as healthcare, education and employment. Currently there are no guidelines about the reasonable adjustments that places of employment or universities can use. They are encouraged to go to charities for recommendations for adjustments such as the National Autistic Society in the UK, but it is entirely up to management to seek this information out and use it. Hence struggles with interviews (Lorenz, Frischling, Cuadros & Heinitz, 2016) and discrimination (Bunt et al., 2020) still exist, and could potentially be a problem for any place that is left to find their own resources on how to create reasonable adjustments.

Only around 16% of autistic people are in fulltime employment and only 32% are in any sort of paid employment in the UK (National Autistic Society, 2016), regardless of the nature of their autism, and research has recently begun examining how to further help autistic people find and succeed in the workplace, suggesting strategies such as a customised employment approach (Wehman et al., 2016) and individual placements and support for autistic people (McLaren, Lichtenstein, Lynch, Becker & Drake, 2017). This suggests that at least in employment, the suggested way to help break down barriers for autistic people is individualised support.

Despite suggested supports, low employment figures for autistic people show that accessing employment and securing and succeeding in a job can be difficult for a number of reasons for autistic people, and some of these difficulties have been found to overlap with difficulties accessing some other services such as primary and secondary education, and healthcare. Autistic people particularly struggle securing employment due to difficulties in interviews (Lorenz, Frischling, Cuadros & Heinitz, 2016), which shows that social difficulties associated with autism that cause issues in the workplace. Workplace rules are known to cause anxiety and confusion for autistic adults due to being unclear or relying on abilities to read between the lines (Remington & Pellicano, 2018) which shows that the workplace may have a lack of effective reasonable adjustments for the employee, which may lead back to unemployment. While there are no official guidelines on what reasonable adjustments to use in the workplace, employers can consult charities such as the UK National Autistic Society (NAS) for guidance on what may be helpful. There is no such guidance for universities when it comes to making adjustments for autistic students. A review on

workplace adjustments promoted the idea of a mix of interventions that take into environmental context and personal factors (Scott et al., 2018), which may prove to be beneficial in a higher education setting, however there is currently a lack of literature to provide evidence for this.

Discrimination against autistic people could be a large barrier to gaining and maintaining employment for autistic people, with discrimination being highlighted as a difficulty across several different European countries (Bunt et al., 2020). Strategies to combat this at a national and international level have been to introduce policies to try to reduce discrimination of autistic people in the workplace. The effectiveness of these policies is too soon to be determined, however if successful the policies, then be used to help discrimination in other areas of life, and reduce the barriers to accessing services such as healthcare, and access to higher education.

In the UK, as per the Equality Act, employers are now legally obliged to provide reasonable adjustments in the workplace for those with disabilities (*Equality Act, 2010*). Autism is classified in UK law as a disability (*Disability Discrimination Act, 2005*), however there is no mandatory adjustments needed anywhere else, such as service users. The acknowledgement in the workplace that autistic people need reasonable adjustments is positive for creating an accessible environment, however it is currently only places of employment being held to this law, and thus it is unclear whether reasonable adjustments would be used in a university educational setting.

Further, an unwillingness to disclose a diagnosis at work could lead to more misunderstandings (Sarrett, 2017), and shows the concern of an acted stigma in the workplace around autism, whether this is the case or not. Prior research has already shown a similar fear over disclosing an autism diagnosis to universities (Mary Rose, Burke, Quinn & Harris, 2019), which already shows some overlap between the barriers facing autistic students in higher education, and autistic adults within workplaces.

Help for those autistic people who do have employment is extremely difficult to find and access, due to a lack of autism awareness in the workplace (Sarrett, 2017). Environmental barriers within offices such as things that trigger sensory distress, or perhaps being in an office too open plan or crowded to be comfortable could also prove as a challenge to

retaining employment (Black et al., 2019). Autistic people in employment are more likely to lose their jobs due to social challenges rather than being unable to do their job and face significant struggles because of the social interaction and expectations of their workplace, particularly non-autistic specific employment suggesting the social challenges of a workplace setting are a large barrier to being able to access employment (Lorenz, Frischling, Cuadros & Heinitz, 2016; Westbrook et al., 2012). Social challenges in this manner could also be a barrier to accessing university, as the social environment and meeting many members of a cohort all at the same time could prove to be challenging in the same way as social challenges occur in the workplace.

### But what does all of this mean for access of universities if you're autistic?

There is a limited yet growing body of literature on the accessibility of universities to autistic people, covering a range of topics such as transition to university and educational support. Increasing prevalence of autism (Hansen, Schendel & Parner, 2015) will mean that more people will be trying to access supports, in the aforementioned services, and likely higher education which may not be set up correctly to the unique needs of autistic students.

Autism awareness in universities is still lacking, with a lot of the participants in a university-wide study acknowledging that the prevalence of autism is rising, but incorrectly attributing the rise in autism diagnoses to vaccinations (Tipton & Blacher, 2013). People were more likely to give correct answers regarding autism if they had someone in their family who is autistic. This indicates that with the right level and familiarity with autism universities could become more accessible to autistic people however little is known about the current state of autism awareness and accessibility amongst university staff, which could potentially affect the quality of their professional practice.

Universities are also not environments exempt from stereotyping autistic people, as these stereotypes appear prevalent across all professions regardless of the contact with autism. The stereotypes most prevalent, though despite being based on highly outdated information and media are those stereotypes that autistic people will exhibit the same behaviours shown in the film 'Rainman' (Huws & Jones, 2010; Conn & Bhugra, 2012; Zerbo, Massolo, Qian & Croen, 2015). Being stereotyped in this way could lead university staff to hold prior expectations of how an autistic students would act and even to some extent what

they look like. This could be a factor contributing to students being unwilling to disclose their diagnosis (Mary Rose, Burke, Quinn & Harris, 2019) and accessing support available to autistic students. Online training has the potential to reduce the stigma in universities which could be an effective method in combating the fears around disclosing an autism diagnosis (Gillespie-Lynch et al., 2015), especially when targeting large numbers of both staff and students, however more insight is needed into whether this would increase the autistic student's population in disclosing their diagnosis in order to access supports. The discomfort autistic students feel at disclosing their diagnosis and the subsequent lack of support resulting from this often leads to a poorer university experience compared to typically developing students (Anderson, Carter & Stephenson, 2017), pushing the case that perceived stigma of disclosing the diagnosis in universities needs to be addressed for students to make full use of any supports already in place, and to create improvements to the supports or new supports entirely.

The executive function deficit theory of autism could also explain why an autistic person may find university challenging as executive function is used to describe functions such as planning, working memory, impulse control, inhibition as well as monitoring and switching action (Hill, 2004), which may cause the autistic person to be less organised than their peers and have difficulties keeping up with managing their time or the administration, or managing assignments with deadlines close together. Autistic people have been proven to have difficulties with organising their time (Van Hees, Moyson & Roeyers, 2014) which could affect their attendance to lectures and seminars. They could then feel demotivated to continue their studying due to the difficulties faced, which may further decrease their attendance to lectures. Difficulties in executive functioning could also cause stress when being assigned several pieces of work at once. It could lead to difficulties prioritising work, and increasing stress levels that may result in procrastination (Rinaldi, Roper & Mehm, 2019), becoming overwhelmed, and the assignments not being completed before the deadline (Van Hees, Moyson & Roeyers, 2014). Administration tasks from the university even just like knowing what to do during the initial transition could be difficult, such as registering and signing up to university as poor time management may mean that administration deadlines are not met (Rinaldi, Roper & Mehm, 2019). Autistic people have difficulties asking for help which means that the confusion around administrative tasks and

disorganisation could become a barrier that is not addressed in a timely manner (Siew, Mazzucchelli, Rooney & Girdler, 2017). This could make registering at university challenging, and the process of submitting any assignments, or even the administrative processes of asking for help such as extensions may seem like a large barrier to getting the most out of education.

The transition to university itself could be a potentially difficult thing to face as past research indicates that autistic people can find transitions in life particularly challenging (Lambe et al., 2018). In particular, transitioning to university as it is a period of large amounts of change in an autistic person's life, where they may end up moving away from their family to a new city, and with many different systems to learn, and new points of social contact to navigate. The anxiety surrounding such a large change may discourage autistic people from applying to university, despite universities slowly adapting to offer more support to autistic people, and to other disabled students. More information is needed on the difficulties of transitioning to higher education for effective supports to be able to be put in place. Transitioning to university would change the routines established beforehand, and based on findings from previous research, this study could find that the change in routine and structure could be difficult to adapt to. This research could explore whether transitions remain a difficult time in autistic people's lives and could look into the aspects of transition to university that are particularly challenging, such as living away from home for what may be the first time.

Independent living is a challenge for autistic adults, with historically a low number of adults with autism living fully independently, and while a higher IQ positively correlates with living independently (Billstedt, Gillberg & Gillberg, 2005), autistic people in university approaching the challenge of living independently in student halls or other accommodation will not be without its barriers. Without support, living alone can be a challenge for autistic people due to balancing work, interpersonal relationships and often autistic people remain independent on their families (Howlin, Goode, Hutton & Rutter, 2004) which could lead to periods of anxiety and low mood. Little support exists for autistic adults living alone outside of assisted accommodation, with previous research recommending that universities provide assisted accommodation (VanBergeijk, Klin & Volkmar, 2008), and so moving in to a shared student



accommodation with no support could raise challenges shown to be associated with change and meeting new people (Lambe et al., 2018).

Mental health problems are known to affect many university students at a higher proportion to the rest of the population (Zochil & Thorsteinsson, 2017), particularly autistic students who are more at risk of co-occurring conditions such as anxiety and depression (Hollocks, Lerh, Magiati, Meiser-Stedman & Brugha, 2018)

It is acknowledged that the university experience can be increasingly difficult if the correct supports are not in place for autistic students (Hillier et al., 2017), and so research has begun looking at effective ways to support an autistic student population over the past decade. An effective way universities could prepare to help autistic students would be the introduction of mentoring as this has been shown to provide effective support for autistic students, providing that the mentors have the correct training in order to provide the most effective support (Hamilton, Stevens & Girdler, 2016). The opportunities for mentorship are not available in every university across the UK, which could affect the accessibility of higher education and limit the choices an autistic student has of finding higher education with support that works for them. It would be interesting to see whether staff and autistic students would also agree that this could be a useful and effective support system for them. Current supports for autistic students are limited, and past research suggests that the most effective supports would be individualised supports due to the nature and variance of autism (Thompson, Bölte, Falkmer & Girdler, 2018).

Should autistic students be given the right support within a university setting, they have strengths that could help them excel and become students with the potential to become high achievers. Special interests are an area of restricted interests pursued with more than an average intensity, so when a special interest is a degree area in which an autistic student studies, they can be a source of academic success and strength (Boven, 2018). Combining a special interest with an autistic person's ability to hyper-focus (Rowland, 2020) with their desire to learn about their special interest, this could lead to better academic performance. With the right supports to develop their academic skills, and their desire to learn, there is no reason why autistic students cannot be as successful as the rest of the student population.

Previous literature shows that the most common problems affecting autistic people's access to services include communication difficulties (Lorenz, Frischling, Cuadros & Heinitz, 2016), fear of the stigma of disclosing their diagnosis (Gillespie-Lynch et al., 2015; Mary Rose, Burke, Quinn & Harris, 2019), and a lack of understanding of autism from non-autism specific services (Sarrett, 2017; Zerbo, Massolo, Qian & Croen, 2015). To establish whether there is an awareness of any of these barriers for autistic students from those working and studying in a higher education, this study will ask a range of teaching and support staff for their experiences and their awareness in providing accommodations for autistic students and any difficulties they expect they would face, and the experiences of autistic students themselves of accessing higher education to try and gain an understanding of some of the difficulties faced. While the data gathered will only reflect the experiences of those involved in the study, it could highlight the possibility of key areas that universities are lacking, or key areas that universities are doing well. The relevance of this research could be primarily to provide an informative basis for future research looking at barriers to accessing higher education, and how the findings relate to the wider literature of the ease of access to services for autistic people.

This research serves to be an exploratory study looking into whether barriers established for autistic people accessing other services overlap with perspectives on barriers accessing university. Although, this work is in no way generalisable to a larger population than those who participate, it may lay the groundwork for future research in this field, and serve to be a stepping stone to other studies looking into this area in the future with establishing a few key areas of interest. A study such as this could establish a basis for further more in depths quantitative research into whether difficulties accessing other services, or employment are also overlapping with the perceived difficulties autistic students face accessing higher education. The overlap of barriers with employment and healthcare will be investigated purely by considering previous literature, and the data collected in this study will relate only to the primary aim of the university experience.

The scope of this research is limited in the fact that it will be using focus group methodology, and will be purely exploratory. It will collect qualitative data for the richness and depth of experience that can be lost in the quantitative studies done previously in the

field and will provide detailed insight into staff perspectives and preparedness with autism and autistic students in universities, and experience of autistic students in higher education.

## **DESIGN SECTION**

Focus groups were chosen as the methodology for this study as to gain an exploratory overview of this topic that would promote in depth conversation between the staff and help gain differing or agreeing perspectives (Morgan, 1996) from those in differing roles within higher education. The type of data focus groups of these nature would be informative (Acocella, 2011), and so provide a basis for future studies in this area.

### **Participants**

Eleven participants were recruited to take part in focus groups using Facebook groups aimed at students, the University of Lincoln's SONA participant recruitment scheme, email, and face-to-face interactions. Staff were recruited from a wide range of roles across the University of Lincoln and Bishop Grosseteste University and the autistic students were postgraduate students who had recently completed a degree at the same university they were studying in at postgraduate level.

There were 9 staff members recruited for a staff focus group from all types of professional cross the university, including lecturers (3), technicians (3) and administration staff (3) to get a wide scope of staff perspectives and experiences of autism in the university. There were also 2 autistic students recruited for a discussion on their experiences of being an autistic student within higher education. Despite there not being enough participants for a focus group data was collected in the form of a discussion.

Inclusion criteria for the staff focus group consisted of having worked in a university for the past 3 years, and could meet in person within the university of Lincoln. Staff from all university roles were invited to participate, and snowball sampling was used for ease of recruitment with staff spreading the word amongst their colleagues. Staff with little to no self reported knowledge about autism at all were excluded from the study.

Inclusion criteria for the autistic students' discussion was to be self diagnosed with autism, or formally diagnosed with autism, in order to encompass the wider experience and

perspectives of university for those with autistic traits when it came to talking about autism. Postgraduates were to have studied for their undergraduate degree in Lincoln.

### Materials

The materials used to conduct this study consisted of a set of questions for the staff focus group and the, written loosely based on the struggles autistic people have been known to see accessing university and a wide variety of services to explore whether any of these overlapped (SEE APPENDIX D).

Participants were given an information sheet, consent forms and debrief forms throughout the course of the study (SEE APPENDIX, A, B, C). The focus groups were also held in rooms in The University of Lincoln. Information and consent sheets are not of the usual format, however the templates provided by the University of Lincoln Ethics Committee were followed in order to get ethical approval for this study.

A university dictaphone and a laptop were used to record the discussions.

### Procedure

Participants were welcomed into a prebooked room within the university, and given the information sheet and consent form for this study. To be accommodating for the autistic students who took part they were also asked if any environmental considerations were needed such as a change in the room lighting or layout.

They were then given the opportunity to ask any questions they had about the study, before the researcher collected the signed consent forms. There were two focus group facilitators in the room to ensure discussion lasted no longer than the scheduled hour, and the moderators explained the rules for taking part including turn taking so that everyone may be able to have an input on the topics, and keeping background noise to a minimum to ensure the audio would be easier to transcribe.

There was then time for introductions, to act as an ice breaker to ease into the conversation before the main topic of the groups was addressed.

Recording devices were set up on university equipment; a university laptop and dictaphone to ensure the quality of the recording for the transcription process.

The discussion was held for an hour around the topics provided beforehand to explore whether barriers autistic people faced accessing other services also overlapped with universities, and what could be done to counteract this.

Once the hour was up, participants were debriefed and thanked for their time, before being told if they had anything to add to the analysis, they could send this to the researcher via email.

The two groups were moderated by two researchers who had GDPR training; this included the primary researcher. Moderation of the focus groups involved ensuring discussion didn't stray too far off topic from the aim of the groups, and for the autistic group, more prompting was needed to encourage discussion. The other researcher in the room ensured that questions were not influenced by any researcher bias from the primary researcher and ensured discussions stayed on track within the time limit. Environmental accommodations for the autistic group were also taken into consideration by moderators so as to account for any sensory sensitivities that may have affected them.

### Ethics

This study gained approval from the University of Lincoln Ethics Committee. While no risks were identified for participants who take part in the study, due to the unpredictability of how the discussions would go and the uncertainty of whether sensitive topics could be discussed, appropriate organisations were listed on the debrief form and the participants were reminded of help they can get for any distress caused by the research at the end of the study. (SEE APPENDIX E).

### Data analysis

Data from the discussions was transcribed from the recordings by the primary investigator who had received GDPR training. The transcripts were then used in the data analysis.

Thematic analysis was used to analyse the data collected using the Braun & Clarke method (Braun & Clarke, 2006). During stage 1, researchers on the team familiarised themselves

with the transcripts, and during phase 2 the transcripts were coded for information, and in phase 3 the main themes were established. Phase 4 was the naming and the finalisation of the main themes (Appendix F).

In stage 1, the researchers read over the transcripts and familiarised themselves with the questions asked and the responses, and ensured data was anonymised by using participant number and focus group.

In stage 2, transcripts were coded initially to tease out all of the important information from the dialogue and put into easy-to-understand terms without any filler language. Codes were then grouped into similar broad categories such as service needs and mental health. These were then further sorted into sub themes.

In stage 3, the themes and codes were reorganised by the primary and secondary researcher, until broad themes were agreed upon with sub themes established within each theme that needed it. Codes were double checked to ensure they did not fit better into a different theme.

Phase 4 was ensuring each of the main themes was appropriately named in a way that reflects the findings of the study. Each of the sub themes names was also checked to ensure it fit within its broader theme.

The thematic analysis was conducted on the NVivo software, used to code and sort into themes before consolidating and renaming them, and identifying sub-themes within the larger themes until a saturation of themes was reached and agreed on by the primary and secondary investigator.

## **RESULTS**

The data from the transcripts was thematically analysed using the Braun and Clarke method (2006). After reading the data a few times and assuring the highest quality of transcription, the research was coded using the NVIVO software for key elements and points in the data. Once all of the main codes had been documented, themes in the data were found and documented, looking for data relevant to each theme, and creating sub-themes where relevant. Having sorted the data, the themes were finalised and named, and reviewed

ensuring that no key data is missing from being sorted into a theme. Six key themes came out of the thematic analysis with some of these themes having sub-themes. These main themes are:

Executive functioning difficulties can affect access to university life

Sensory sensitivities cause barriers to education

Social difficulties can make university stressful and difficult

Support services are very difficult to access for autistic students

There is very little autism awareness within universities

Transitioning to university can be a challenge for autistic students

Full data analysis nodes and themes can be found in the document Appendix G

### **Executive functioning difficulties can affect access to university life**

As executive functioning difficulties can cause barriers to access across other aspects of life for autistic people such as primary and secondary education (Freeman, Locke, Rotheram-Fuller & Mandell, 2017; Ryan & Marshall, 2018), and findings in higher education (Rinaldi, Roper & Mehm, 2019) it is not surprising that this theme emerged from the data analysis when looking at accessing university.

Autistic students find it helpful when lecturers give information in advance, which is something lecturers have noted that they do try to do however they may not be aware of the extent in which it would be needed. Lecturers understand that providing lecture slides beforehand for the autistic students to read in advance and give them time to process the information is helpful, and that providing advance warning about any learning materials or content that may trigger phobia in order to limit the amount of anxiety faced:

**Staff 1:** *I think what I find useful is I always tend to put the lecture slides on beforehand and if there is anything... that's diff- that I'm going to do differently in the session, if there are*

*going to be any videos or anything like that that I think are different from uh, typical like session then I'd always put it in the notes, also when I had animal assistant intervention sessions I obviously asked for phobias or allergies to dogs and things like that, so I tend to give students a few days notice before the actual lecture in an announcement or to the lecture slides or something and I just make sure that they're emailed that information beforehand so they can come to me and actually say if they're, if they can see any issues.*

Autistic students themselves said they would like a lot more examples of how to do the assignments, for example a template or an example of a completed assignment in a different topic area that uses the same structure. Examples are clearly understood to be important to autistic people to help with executive functioning difficulties and for knowing how to complete the assignments in the way required, and to be given the time to digest information ahead of the lecture in which it will be expanded on. Other adjustments that would help autistic students keep track of the information in lectures would be subtitles in videos, and slide numbers on the PowerPoint so they could come back to the slides they missed later on should they become distracted or have difficulty processing the information.

Much of the information in this theme pertains to universities being difficult to access due to having irregular routines, often ones that are not efficient with lectures and seminars being scheduled long enough apart for a break, but too short of a time to be able to work during this break. Having a good schedule is important to make the most of education but for some the way the lectures and seminars are organised it can be unsatisfactory and impact on autistic students' motivation to keep studying during the day:

***Autistic student 1:*** *Yeah I found in general having a lecture around 10 was kind of the sweet spot cause I've had enough time to wake up, I feel alert, but then um, if that's your only lecture I still feel like I can go do more work and I will go and yeah go to the library and study or do whatever I needed to do whereas if it's at like 2 or 4 you kind of, it's at this weird point where like it's really hard to start working and then once you've finished the lecture it feels like you should be done for the day and you just can't quite get that, actually no. the worst are when you have one at 10 and then one at 2*

***Autistic student 2:*** *yeah*



**Autistic student 1:** *And you've just got this weird chunk where you don't feel like you should go home but you don't feel like there's enough time to really sit down and focus on anything*

Unpredictability of when seminars would be occurring leading to an irregular schedule was also a cause of frustration for autistic students:

**Autistic Student 2:** *Umm. So when I was an undergraduate ummm. I'm trying to think what my timetable was like. So one of the main things I struggled with was when you had irregular seminars*

**Autistic student 1:** *Mmm*

**Autistic student 2:** *Like especially if they were early as well cause a lot of my stuff was in the afternoon so it just kind of broke routine more, um...*

Combined with suboptimal schedules, this could lead to breaks in an established routine which could cause stress and anxiety (O’Nions, Happé, Evers, Boonen & Noens, 2017) or a lack in motivation to work and increased procrastination levels (Ferrari & Roster, 2017).

### **Sensory sensitivities cause barriers to education**

Staff were aware that autistic students could have different sensory needs than the rest of their cohorts, and that these could potentially result in autistic students missing lectures due to anticipated discomfort:

**Staff 5:** *I'm gonna go back to something I... that learnt from you from your lecture that you did, there's quite a few things especially if it's like a large cohort... If for some reason they're really late they might not wanna go or that might obviously impact whether they actually turn up or not, they might not want to go in the first place because the idea of being around so many people... that they don't know... things like that especially... obviously if, or even where the lecture is, if it's quite a bright room or they've had a past experience where they weren't comfortable in there they might not wanna go because of that. I think there's quite a lot of environmental factors as well as situational factors that might affect them actually*

*whether they want to go to lectures and then... with seminars if they have to contribute a lot... that might put them off as well, so I think there's quite a few factors.*

This was also confirmed by the autistic students in their discussion, as both had admitted that it helps to be late to lectures sometimes to avoid discomforts in finding the best place to sit in the lecture theatres, and having to move past so many other students to get in and out of a seat. They say that if they cannot get any benefit from the lecture they may as well not show up, so sensory sensitivities and less than optimal learning environment:

**Autistic student 1:** *[agreeing sounds] Yeah, I think temperature is a big reason for that cause I- I'm really sensitive to any kind of temperature change so especially in the summer when you're in those rooms and it's hot and cramped and everyone's loud and no one's like... focusing it's just... yeah I may as well not show up*

One person in a teaching role within a university admitted to not considering autistic sensory sensitivities in lectures unless being directly asked to by a student after a particularly distressing lecture, which could indicate that autistic students' needs are being ignored unless they can request the adjustments they need for themselves. Autistic people can have difficulty asking for help due to a fear of not being listened to (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018). If autistic students feel they are unable to ask for adjustments that are easily available from lecturers such as dimmer lighting, and warnings on videos with loud sounds or adjusting the volume. Staff and students acknowledged that sensory sensitivities can make lectures very uncomfortable that would create a barrier to autistic students wanting to make the most out of their education.

### **Social difficulties can make university stressful and difficult**

Both staff and students in discussion realised and spoke about that there were communication barriers to autistic students' education. Staff acknowledged that they did not necessarily know the best ways to talk about autism, or even the best ways to talk to autistic people and what methods to use or language to use:

**Staff 7:** *Exactly and this can be a quite a... you know like a... like an obstacle in a conversation, immediately just because there's a perceived intention that lies or may not lie behind the language that's used... but you know if there's no sort of.. if, if you said there's no*

*exposure how would you know that you know autistic or with autism... well... you have to be careful, depending on who you talk with. Because if you're talking with a health professional that's again different.*

**Staff 1:** *Yeah... but it depends because individuals as well can prefer... one person would prefer autistic and another person would prefer with autism... but you- yeah I completely agree it's not- there's not really a standard of how you approach it or how you speak.*

There can be various different communication preferences for all autistic people such as discussing the issues with understanding and learning the structure of emails and what levels of politeness and professionalism to use within them, and how when someone phones them it can cause anxiety that there is an emergency or something is wrong. There is no universally clear preference for indirect contact with staff or peers as there are down sides to all forms of communication:

**"Autistic student 1:** *No yeah... emails are the worst part of... like worse than phone calls for me, cause with phone calls you can just fuck up and then apologise and then it's fine but in the emails it's a whole drawn out thing"*

**"Autistic student 2:** *I get that as well, I think I prefer the kind of more... if it's more informal I prefer email, formal, phones sometimes but, no I think I still prefer email, but it's harder to get started with that"*

Having no clear indirect communication preference means this could create challenges for staff wanting to talk to and reach autistic students via email. In person conversations were surprisingly preferred by both autistic students in these discussions, despite staff predicting there would be a preference for email communication. This shows there is no clear preference for communication that is known to and shared by staff and autistic students, suggesting a barrier to education that could be difficult to counter.

Social difficulties placed on autistic students by staff can cause difficulties in universities, due to things like the struggles of navigating group work in seminars and lectures. This was acknowledged by both staff and students however staff did not think there was any way to remedy this, or even if they should remedy the struggles by doing things like removing group work, as group work skills would be important in preparing students for later life:

*Staff 7: and to be honest I'm not saying that we should rule [them out], because group work is gonna be necessary in their professional life, presentation is gonna be necessary most probably in their professional lives as well so it needs to be built up I think... But then we can find ways to somehow make that easier y'know building up rapport building up confidence... getting loads of exposure y'know it's it's... okay that's that's your first presentation you know what don't worry if you wanna sit it out okay, have a look at what other people do, how do they cope with their stress, how do they cope with the anxieties... everybody's y'know everybody's stressed or it's a different level and a different experience of that stress, but maybe the same sort of... solutions that work for other people maybe they're gonna work for you or... not one of them but maybe you're gonna use all of those solutions all of them... the different things that other students try to incorporate in their [day] or how they... deal with presentations and loads of people speaking, loads of people.*

While staff perceived that group work seems unlikely to be ruled out, another anxiety of autistic students is being called on in a crowd to answer a question, such as in a lecture in front of their cohort. Lecturers acknowledged that this happens during teaching and suggested they be mindful of it as it provokes anxiety, and that in general they need to be more mindful of any students with anxiety or communication difficulties. Some challenges around communication difficulties like group work will be difficult to find an effective solution for, but there are things that could be done in other areas to prevent anxiety such as not picking on students to answer questions randomly in front of groups.

### **Support services are difficult to access for autistic students**

This theme broadly shows that teaching and support staff and autistic students in universities see support as being very difficult to access, with varying different barriers getting in the way of support that could be effective. There were four sub themes within this broad theme as well as other broader data that still fit into the theme. The sub themes are:

Mental health support for autistic students in universities is lacking

It can be difficult asking for help

Support is not cohesive or organised

Support services are overwhelmed by numbers, and a lack of funding.

### **Mental health support for autistic students in universities is lacking**

The data in this theme covers what staff and autistic students see as potential problems, and also covers some suggestions on how to improve mental health support for autistic students. The viewpoint that support and teaching staff had regarding their knowledge of the mental health services was that they did not know how to help students other than to send them to student mental health services. They did suggest that they could do smaller things to help but this came from their own ideas of what they thought was best rather than having come from any official training:

***Staff 6:** I think just as a... as a case, that an example one of the, the challenges that I'm aware of is that students will go to, like say go to wellbeing because they can't cope but actually, that didn't happen overnight, that's an accumulation of little things and actually, when you get down to the nitty gritty in the core of the issue... it's it's not necessarily just in mental health it might be that actually, something is going on at home the phone's rung and for the rest of that lecture they're going why'd that person ring, is there something wrong, I just wanna answer my phone I just wanna know if everything's okay, and actually by going back to... say the academics and going please if this person rings I just need to step out, take a phone call and come back in. Again anxiety levels will drop, they can then get back into the seminar and things like that, and that can happen across... across anything y'know actually it doesn't necessarily, whilst you refer them to wellbeing actually the, the issue... while might be emotional at the time may not necessarily be... once, once they get past that emotional stage where they're upset or distressed it might be that really really tangible things can be put in place, to overcome that it might be that they, they need just a conversation about their academics they're not coping with their academic side of- like their studies, and actually putting something in place to, get them back on, back on track.*

There were suggestions of staff taking mental health first aid courses and suggestions that these and already been put in place and had been effective at other universities, and seemed to be considered a good example of balancing how much staff are expected to do to support students as opposed to just sending them to a service where they cannot be sure on the quality of the support they are getting.

The autistic students in the discussion pointed out more flaws in the mental health systems they had been put through and were disappointed that the help they received was just a 20-minute discussion followed by the same leaflets they were given every time they tried to access support:

**Autistic Student 1:** *"they just do not have enough time to properly talk to you and work out what's wrong and the only way to get past that is to get therapy which is like months of build up which when you're suddenly feeling overwhelmed and having a panic attack you don't have a month to spend and like it doesn't really help when you know you're freaking out so you're like okay I need to go to wellbeing this is the point of wellbeing is to help me out in this moment you sit down you wait the 20 minutes or so, you go into a room, you spend 10 minutes just telling them about what's going on, they hand you a pamphlet and then let you go and it's like I know all this stuff you know, we've- I've had this stuff enough time I have so many copies of pamphlets and they haven't helped."*

Overall mental health support was regarded as insufficient by all the demographics across the groups spoken to, with teaching staff in particular showing concern at how much they were expected to do to help and what they could feasibly do more to help. Mental healthcare is seen as difficult to access and is not set up in a way that benefits autistic people.

### **It can be difficult to ask for help**

Support and teaching staff showed concern that autistic students waited until they were at breaking point to ask for help, leaving things too late which then impacted on the help that they were able to give, or only being notified to give help at the last minute:

*the problems if they are underlying over the course of the semester earlier on... we as personal tutors don't know about them because they're not manifesting in students having issues... it's only at the end of the semester and then yes likelihood is some of them will just have left everything too late and completely panicking about it entire cases absolutely, but I don't know that at the time.*

Staff in direct support of students could feel helpless when having to see a struggling student only get help when things are very last minute and panicking, as issues could have

been resolved if they were spotted beforehand or had better support before they got to breaking point. Relying on autistic students to be proactive and seek support themselves is difficult as the autistic students commented that to get help, they had to do things their diagnoses specifically said they are bad at:

**Autistic student 1:** *Yeah I've gotten, like the help I've gotten as been pretty good, It's been complicated and annoying and I've had to do lots of things that er, my diagnoses have specifically said I'm bad at which doesn't help, like going to meet strange new people and phone people up yourself and you know there's kind of an extra layer of independence you have to do to get the stuff when you're the one who needs the help, it's a bit...*

**Autistic student 2:** *yeah, I think that's, that's the reason why I never actually registered with wellbeing, I wanted to I knew I could get help through them and software and things that would be helpful but then you go there and they, then you have to do something and you kind of feel unsure about that and, it's like you kind of need help with it but they can't help you unless you're registered with them and kind of circle*

The stigma of asking for extensions and asking for support was also commented on suggesting that in universities there is an air of shame around needing extra time to complete an assignment because of difficulties encountered. The stigma surrounding it means autistic people would struggle to ask for an extension, especially if they weren't sure whether they would get one or not.

### **Support is not cohesive or organised**

One of the largest discussion parts regarding the construct of the support systems is that there is no organisation. Support for autistic students comes in pockets and students have to go to each individual point of access to be able to get the support provided. There is no communication between the different points of support and so the services are difficult to access largely to their disjointed nature, particularly not just for autistic students but for those with other neurodevelopmental conditions, and especially those with more than one neurodevelopmental condition such as autism and ADHD:

*so you've got a student's services you've got the [count] which is er... supporting learning development... and then you've got the program lead and... that put certain things in place*

*but... they... it's not just... like you say it's not just one plan... and even, there were even kind of things that we've tried to iron out to do with tutors that they get different tutors for different things... it's now the same one but.. again it's that kind of... in little bits. If you have dyslexia you go over here if you have... something els- you know if you have autism you go over here... but actually you also go over here and it... doesn't... necessarily coordinate.*

**Staff 7:** *It's exactly what you said, I think it's the coordinatory body that's missing, so one hand doesn't know what the other hand's... hand does. There's no common... like, uh... forms and... you know just documentation and the information's not... kinda like... ready available for the different bits for accessing. it's it's the coordination above all that's a bit...*

Following this, staff also felt that there was no proper system in place to evaluate how effective any supports for autistic students are, and that there was no one who really cared about this as long as that supports were in place so that a checkbox could be ticked just to say that they were there. This could lead to services that do not do what they are supposed to, and only do the bare minimum to keep that checkbox ticked. All staff agreed that autistic students should be sent to the appropriate service for support but this becomes incredibly difficult if the support is not organised or not adequate to meet autistic students' needs especially when staff are not aware of all of the many different points of support.

### **Support services are overwhelmed by numbers and a lack of funding**

This subtheme encapsulates a lot of reasons for the issues the participants discussed in the other subthemes of service. The university support systems do not have enough funding and are too small for the number of students attending the university, with people finding them so difficult to access that they may as well not exist in the first place:

#### ***Are you aware of the services that are available for autistic students?***

**Autistic student 1:** *Yes but we can't access them, because the uhh NHS is so overworked here that we can't get a proper autistic diagnosis... I've been aware of them for many years and I still haven't been able to access them the entire time so they may as well not exist*

Staff have been so concerned by the lack of response and the amount of numbers accessing the services, and have expressed frustration that even when they are that concerned about



a student they take them directly to the support centres, it will still take a long time for the student to get support. This then leads to inconsistencies in the support provided due to different pockets of support getting unequal amounts of funding with some parts of the system being considered acceptable and others being less than optimal. It was agreed that a lack of funding of the NHS meant that healthcare was not accessible, and that the large numbers being sent to the overwhelmed mental health centres could not get support due to a lack of funding to expand them:

**Staff 4:** *School of computer science sends hundreds of students, yeah.*

**Staff 3:** *I know we, we send a lot of students but my feedback from my personal tutees has sort of been better this year it has been before because less... you had a problem and you just, you sent them along and they just had to, y'know, crisis point and there was nothing available when it already is a problem.*

This has led to the lack of availability of support, which could tie in to all of the other subthemes resulting in autistic students being less likely to ask for support, the less than satisfactory support available and that services are not cohesive or organised and are affected by different quality in services due to differing funding available. All of these constitute as barriers for autistic students accessing healthcare and are a mix of both personal factors due to autistic traits such as difficulty asking for help (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018), and external factors like the lack of funding affecting the quality and cohesiveness of the support.

### **There is very little autism awareness in universities**

A lack of autism awareness in universities covers large areas such as staff training, general knowledge and stereotyping of autism, and listening to autistic people rather than making assumptions about what they need without talking to them. This broad theme encompasses the perceptions of autism awareness within universities and also contains two sub themes.

These sub themes are:

- Autism awareness is based on general knowledge, stereotyping and personal experience rather than training

- There is no helpful way of learning about or understanding autism for staff to use

Autistic students in this study felt like autism was not factored in or accounted for outside of any sort of lessons or lectures on autism itself. This indicates that it is not a factor widely acknowledged in the university setting, and even lecturers on autism have not had any sort of consultation with anyone higher up in the university regarding autistic students or what sort of supports there may be needed:

**Autistic student 1:** *I hav- I haven't seen anyone make concessions because of it but I haven't seen anyone be hostile because of it, it's just a non factor really*

**Autistic student 2:** *Yeah*

**Autistic student 1:** *I've never, again outside of autism lectures it's never been a thing*

This means autistic students could feel invisible if their difficulties are not acknowledged or validated, and with this little autism awareness within the university it means that there could be increasing challenges due to a lack of awareness. Staff admitted to not knowing that they should make any adjustments for any autistic students, largely because they are not told who in their cohort is autistic and may need adjustments, and because they do not factor in the need to make any adjustments to their teaching styles unless specifically asked by a student for a specific type of support.

### **Autism awareness is based on general knowledge, stereotyping and personal experience rather than training**

Staff agreed that any autism awareness that does exist within universities is due to staff having to educate themselves on autism, and they do not always do this in ways that give the most accurate information. They were aware that people got their information on autism in universities from pre-existing stereotypes about autistic people such as the characterisations of autism in the media, or through their own experiences with autism both inside and outside a university setting:

**Staff 1:** *There's... I think there are a lot of... kind of events that are going on for things like autism awareness week but actually how many autistic individuals are involved in that aware- you know in actually portraying that. Um, I myself have worked before I [paged] here*

*I worked with children, uh, autistic children for about two years and I've seen ... various different ... versions if you like, to- you know, differences within autism but I think there is a certain stereotype that everyone... perceives, especially people that haven't necessarily worked with autistic individuals or people that haven't come across them in their families...you know it's... I've ... very recently come across people thinking that you know, autistic people walk around with massive headphones in the shops because they don't like noise, autistic people a lot of them don't do that and actually I've had people say to me oh this... I've found out that this person is autistic and I didn't even know about it... well what do you expect. But I don't think... I don't think- I think people feel that they should see a difference in autistic individuals and they don't necessarily see that difference so I don't think that they really know what autism is.*

They were aware that the stereotypes were not accurate representations of autism, especially considering how diverse of a neurotype autism is, but recognised that a lot of issues around peoples understanding of autism was based on stereotypes that suggest autistic people should look and behave in certain ways. Understanding of autism seems to be limited to those who have experience with it, with the autistic students saying that the staff most likely to be understanding of autism were the ones who taught about and researched autism themselves:

***Do you think the staff in the university are aware and understanding of the autistic students?***

***Autistic student 2: Some of them***

***Autistic student 1: The ones who study autism are***

***Autistic student 2: Some of them... [laughs]***

One of the staff members did raise concern over the point that even those with knowledge about autism within the university such as those who taught about it, had never once been asked about what sort of provisions autistic students may need or how higher education can adapt to become more accessible to them. Students are also not consulted about what kinds of adjustments or support they would like either, instead having to rely on the knowledge of universities to put adequate support in place based on their own knowledge.

### **There is no helpful way of learning about or understanding autism for staff to use**

Staff did not know of any useful training they could go to regarding autism, in order to raise their understanding or to help them make adaptations in their work, and they also expressed their concerns if any sort of training system were to be put in place. A lot of the concern seems to come from the heterogeneity of autism, how if they are told to put in supports it may work for some autistic people but not all. With autism being so varied there is a lot of concern about how much there is to learn about it, and whether it would become overwhelming if they were given a long training course on autism:

***Staff 7:** But that's, that's what's really difficult with autism... because you've got such a variation there... you know, and and, some of the questions that what... we were asked... were then companies as kind of like... so what do I have to know about autism so what it is, what is it what are the characteristics, tell me what... well it can be this or not, it can be that or not it can be that or can be the opposite or can be [inaudible]... Ok then so what shall I do, what what what is the solution for me, what sort of strategy can I implement what is the set ru-regulations or the set guidelines the directive that I have to follow, and... and... this is, this is what needs to change, the sort of understanding that it's not, you know there's no specific rule it's not black and white black or white it's not... it's not... concrete. It can be this, or that. It is a spectrum... it is a spectrum that we're talking about and not a set... set of characteristics.*

The current guidelines that staff find using the NAS website or other sources, are perceived to go against what they are told is engaging teaching, thus creating confusion about how to best create adaptations that will not impact on the other services the university provides for students. Staff also have no awareness of the support systems available to autistic students, and are told to just send students to wellbeing. This leaves them feeling that they wish they could do more but they cannot even promise any support to autistic students as they are unaware what student wellbeing services can do for them:

***regarding... the emotional difficulties and comorbid conditions that can come with autism, would you be confident in dealing with an autistic student who asked for help regarding the university's mental health services, and what do you think may be the reasons for that?***

**Staff 5:** *I don't think I'd confidently be able to... provide service for someone I think the only thing that I would know to do or could think to do is refer them to wellbeing and that is... as, as far as my knowledge goes in that, which is quite disappointing.*

Staff would likely at least benefit from knowing what support was available so they could tell struggling autistic students' what kinds of support they would get, or where else to go for help. With the differing roles staff had in the focus group such as technicians, lecturers and administration staff, it was agreed that staff would not need to know everything about autism, and one training program for teaching staff would not be beneficial for those in non-student facing roles. It was not agreed on just how much staff should know, leading to a debate with no conclusion, only that it would be difficult and unnecessary for staff to know everything about autism.

Staff within universities, according to both the staff themselves and the students in the sample, do not have adequate autism awareness. Current awareness is based on stereotypes, media portrayals and any personal experience, which could lead to inaccurate information or gaps in knowledge. More autism awareness is needed but it is unclear how much awareness the participants of this study think would be beneficial.

### **Transitioning to university**

Transitioning to university was acknowledged as one of the key challenges for autistic students when first coming to university due to the amount of change; change in routines, change in people, change in workload and style of learning and change of supports available. Staff in the focus group predicted that it would be one of the key areas of struggle that autistic students face, more so than other students:

**Staff 7:** *The problem is that we know that's you know that transitioning periods are associated with y'know being a typical problem for autistic populations that it's... yes there's a baseline being a problem for all students really, but that may be more problematic for some, some autistic people, some autistic students... because of the changing environment, the changing social support, the available support... y'know who to, who to go to okay which office is it where is it on campus, practical signs and non practical signs as well...*

In particular, living in student accommodation seemed to be highlighted as an issue by all participants of this study. Not being able to control who you live with is a source of anxiety for autistic students which staff picked up on, and one autistic person within the study opened up about having been assaulted in student halls a few months after moving in:

***Autistic student 2:*** *I was assaulted in my flat in first year, on Halloween*

***Autistic student 1:*** *Oh... oh fun*

***Autistic student 2:*** *That's why I moved*

In conversation about what living in student halls was like as an autistic person they felt like they were confined to their rooms, it being the only personal space they had, and then having to share a kitchen and living quarters with other people they did not necessarily like or get along with well. Staff voiced that autistic people living in student halls would have a harder time adapting to university than autistic people still living at home with their family. Despite this, the students said they felt no homesickness despite expecting to feel it and that the transition was fairly easy, contrary to the staff beliefs.

To ease transition to university for autistic students, it was suggested that the university should engage with autistic students earlier, and allow them to come to the university and enrol, and move in before other students. This would allow them to have more time to get used to the environment without the barriers of large crowds of students all trying to do the same thing. It was said that some universities are beginning to plan ahead to welcome more neurodiverse students including autistic people. It was also commented that autistic people may be more prepared if they had good support from their college or 6th form before their transition to university.

## **DISCUSSION SECTION**

The main findings of this research were six key themes that were shown to be the perspectives of what autistic students struggle with. Some of them overlap with the existing known difficulties autistic people face accessing other services but applied to university settings, and others were challenges unique to university settings. The research aims for this study were to gain a range of different staff and autistic student perspectives on barriers for

autistic people within higher education settings, and a range of perspectives were gathered. Mostly staff of all different roles and the students agreed on many difficulties that autistic students could face, but there were differing opinions on what solutions should be made available such as training, and how extensive it needed to be. Overwhelmingly, everyone in the study agreed there was not enough autism awareness within universities.

With this study it was hoped an understanding would be gained about the differing perspectives particularly of those in differing staff roles, such as student facing and non-student facing roles, compared to that of autistic students themselves. While the samples were not large enough to be conclusive, it could highlight areas that may be useful in informing future research in this topic area. Perspectives in this research have been regarded as the best way to explore the barriers, as with physical disabilities there are objective measurable barriers such as stairs and inaccessible corridors. There are fewer to no physical impairments when it comes to autism, so the barriers are invisible, hence the focus on qualitative research and the focus on gathering these perspectives.

#### DISCUSSION OF EXECUTIVE FUNCTIONING DIFFICULTIES

Executive functioning difficulties not only cause problems accessing primary and secondary education (Freeman, Locke, Rotheram-Fuller & Mandell, 2017; Ryan & Marshall, 2018) but they also prove to be a perceived barrier to higher education by both the staff and the students in the discussions held. This is consistent with findings from past research looking into other services that autistic people struggle accessing because of executive functioning difficulties such as struggling with making appointments at the GP (Hillier, Galizzi & Ferrante, 2017) or timekeeping (Ryan & Marshall, 2018) and processing different information at once (Gibson, Kaplan & Vardell, 2017). All of these issues support the perspectives found in this study that executive functioning difficulties could create a barrier to autistic students in higher education.

Routines are important to autistic people to help them structure their daily lives (Lambe et al., 2018) and so the perspective that autistic students would struggle from the irregularity of seminars and lectures at inconvenient times of day has a lot of face validity, and has been

supported by (Lambe et al., 2018; Lei, Calley, Brosnan, Ashwin & Russell, 2018). Difficulties managing routines could result in increased stress and anxiety (Austriaco, Aban, Willig & Kong, 2019) which could mean increased procrastination levels (Rinaldi, Roper & Mehm, 2019), or truancy from lectures or seminars. Irregular seminars such as those discussed by autistic students, or lectures structured in a way that made breaks and studying difficult could also show a less than optimal routine, which would disrupt how effective the teaching is. A lack of routine has also been shown to affect autistic people in several other areas such as bedtime for children (McAuliffe, Thomas, Vaz, Falkmer & Cordier, 2018) and daily chores and tasks (Coussens et al., 2020).

The data showed a mix of perspectives both on the barriers to autistic students in university, and perspectives on what could be done to alleviate them. Regarding executive functioning difficulties, suggestions on what could be done to make life easier for autistic students included giving more examples and templates for assignments. Simple fixes such as this could be used to manage issues caused by executive functioning such as difficulties with administration tasks (Brugha et al., 2016), particularly if autistic students know what to expect and have a clear example of how to do things. Examples and receiving learning materials beforehand could help with the amount of time it takes to process something, which can take longer for autistic people (Hill, 2004). Lecturers also said they could offer tips on time management when it came to learning and studying the materials provided, but they saw a large portion of the issue was that the struggling autistic students often asked for help too late. This perspective could be backed up by the research showing that autistic people struggle asking for help (Dymond, Meadan & Pickens, 2017) and so would be more likely to struggle with their time management and establishing an effective routine.

Executive functioning difficulties are considered to have a detrimental impact on the quality of higher education for autistic students as schedules and organisation are important, as is help with administration tasks. Some staff in this study did share that they put their learning materials online before their lectures or seminars so students could familiarise themselves with the material before they go through it in face-to-face teaching, however, this was left up to individual staff members as to whether they wanted to do this or not and was not a requirement in order to make lives easier for autistic students and those who may take a little longer to process information. While autistic students had the opinion that providing



the information beforehand was helpful to them, the provision of these adjustments of having access to the learning material was optional. To make a difference in the quality-of-service provision, it could be mandatory that all learning materials are available online before lectures and seminars.

Service provision in universities is currently based on a system that is not designed with autistic students in mind, and if they manage to overcome the barriers to entry (Hillier et al., 2017) teaching is based on what the lecturer deems beneficial for the average group rather than considering the needs of differently-abled students, and those with more individual and specific needs.

These findings indicate that a lack of routine is an issue within a university setting, and therefore to look for adjustments it may be worth considering looking at other fields that are more accustomed to providing support for autistic people such as special education (Goodall, 2018). If higher education has unpredictable and irregular routines, the results from this data would suggest that further research could be done on to the likelihood that autistic students will attend lectures and seminars with an irregular routine as opposed to a regular fixed routine. Establishing a clear unchangeable routine may improve the attendance of autistic people to lectures, as they know exactly what to expect and how to schedule their days around it.

This research shows the overlap in difficulties caused by executive functioning differences in accessing higher education, with healthcare, employment, primary and secondary education and mental healthcare. This suggests that supports already available may be adaptable to university settings, so that universities are not starting from scratch trying to provide their own support for autistic students with executive functioning issues. Staff and student opinion in this study highlighting executive functioning issues indicate this is an area where autistic students would benefit from more support.

#### DISCUSSION OF SENSORY DIFFICULTIES

Largely the main perceived barrier to autistic students discussed in this study were the designs of lecture rooms and learning materials that were not set up to cater to anyone with different sensory sensitivities to the average student population. Being in an uncomfortable

sensory environment could decrease concentration levels (Talay-Ongan & Wood, 2000) and even make it less likely that an autistic student, or any student with sensory processing difficulties would attend. Issues ranged from the design of lecture theatres themselves with poor equipment such as crackly microphones and uncomfortable temperatures, to lecture provision themselves with lecturers noting that the volume of videos had caused distress in the past to students.

Poor design has caused universities to be accessible to many disabled students (Hannam-Swain, 2017) and while an effort is being made to build new facilities with disabled access, and to adjust older facilities to be disability friendly (Shuayb, 2020), with autism being a hidden disability it is often overlooked. Those in teaching roles and student roles were more likely to be aware of the problems autistic students faced regarding sensory sensitivities such as flickering lighting, and understandably ideas for any sort of solutions were few and far between. However, this was not always the case as one staff member in a teaching role admitted to not considering sensory sensitivities at all, and another admitted to only considering them when a student told them they got overwhelmed by sensory stimuli in their lecture. This shows that there is still a level of awareness that needs to be addressed in order to make lecturers more accessible to autistic students. Sensory processing issues could mean that autistic students will deliberately miss going to areas with high levels or sensory stimuli, like many autistic people avoid any sensory situations that are difficult such as GPs and finding primary and secondary school classrooms challenging environments to be in (Mason et al., 2019). This in turn could have a detrimental effect on their attendance and they will not be able to get the most out of their higher education learning if they feel they have to avoid places within universities due to discomfort experienced when there. These findings are consistent with previous literature of autistic people avoiding places with sensory stimuli they find distressing, and shows that more in depth research should be carried out into the kinds of sensory stimuli that can cause difficulties in higher education, and ways to ameliorate these difficulties.

Previous research in primary and secondary education suggests that the best ways to alleviate sensory overload are to provide the option of a quiet room, try to minimise loud noises or noises that could count as a distraction and remove focus from the lesson, and for teachers to have more autism awareness training (Jones, Hanley & Riby, 2020). Universities

could provide the option to leave and go to a quiet room if the sensory stimulation becomes overwhelming for autistic students, and provide more options for quiet places to study than just the library so there is more choice. Universities could also look into autism awareness training for its staff particularly focusing on sensory sensitivities so staff can prepare their teaching material with sensory stimulation in mind and adjust them to be more accommodating of those with sensory processing issues including autistic students. This research also shows there could be a large overlap between the sensory sensitivities autistic people experience in other parts of their lives such as accessing healthcare (Warner, Parr & Cusack, 2019) and education (Goodall, 2018), and so future research could be conducted trialling methods of helping sensory distress in universities that are shown to be effective elsewhere.

#### DISCUSSION OF SOCIAL DIFFICULTIES

Social communication difficulties are one of the key factors when it comes to diagnosing autism [5th ed.; DSM-5; American Psychiatric Association (APA), 2013] so understandably autistic people have communication difficulties over the course of their lifespan (Sonido, Arnold, Higgins & Hwang, 2020) which affect their access to services as phone calls can be exceptionally difficult to make (Ghanouni et al., 2020). In universities both staff and students in the focus groups acknowledged differences in communication were a large obstacle to quality of teaching and providing support. Autistic students have varying communication preferences, and what one autistic student prefers may not be ideal for another (Cummins, Pellicano & Crane, 2020). This means that there is no one means of communication that would work for all students, and that to have a system truly effective there would need to be individual needs taken in. The issue with individual needs being taken into account is that communications with large cohorts would have to have the details of students that need to gain the information in a different format, which would increase the workload and responsibilities for teaching staff.

When it comes to different methods of communication, the main issues for the autistic people taking part in this study, and other autistic people in previous literature are the anxieties from using a communication method they do not prefer (Cummins, Pellicano & Crane, 2020), and the social expectations of politeness and etiquette around them

(Atkinson-Jones & Hewitt, 2018). Confusing rules around communication could lead to a barrier between staff and students that the staff in this study had no suggestions on how they could remedy this. They admitted that with no exposure to autistic people before, or at least not exposure they were aware of, it was hard to know where to even start when considering to make adjustments for autistic people with regards to communication. Methods that have been effective in other areas are text-based meetings, and increased awareness of the differing communication needs of each autistic person (Cummins, Pellicano & Crane, 2020). Changing the university systems to trial these methods would be interesting for future research, to see if higher education communication can be adapted in this way.

Social skills training for autistic people has been shown to be effective at improving knowledge on how to approach email etiquette and phone calls in other areas, and how to approach others in conversation (Connor, Sung, Strain, Zeng & Fabrizi, 2019). In higher education this could benefit autistic students and improve their confidence particularly with helping reduce anxiety and depression, and improve their social confidence and participation (Connor, Sung, Strain, Zeng & Fabrizi, 2019). This could lead to a higher participation in group work and in other aspects of teaching, boost social relations with peers and lead to a more improved educational and social experience of higher education. If staff make adjustments for autistic people, and if autistic people have support to include their communication skills this could lessen the communication gap and make higher education more accessible. This also shows that communication difficulties in other areas overlap with higher education and communications trainings that have been effective for autistic people in other areas may also be effective for autistic students in higher education, so the support to many difficulties could already exist and be adaptable from other fields.

Another issue that social difficulties can cause when it comes to being able to access higher education is group work, and this was acknowledged by all participants of the study. Group work is a challenge for autistic students with many having concerns about taking part in it and being able to succeed. As staff mentioned, however, group work is a part of adult life, and autistic people are known to struggle with group work in other areas such as employment (Lee, Chun, Hama & Carter, 2018), and so university could be an opportunity to

provide help for the autistic students to be able to prepare them for group work not only in their education but later in life too.

Other simple solutions to help improve anxieties about participation in learning would be to reduce the chance of randomly being called on to provide an answer. Randomly calling on students for answers and putting them on the spot provokes anxiety in the typical student population (Broeckelman-Post, Johnson & Schwebach, 2016), this would likely cause anxiety for autistic students who are already more likely to have anxiety conditions such as social anxiety (Spain, Sin, Linder, McMahon & Happé, 2018). Staff acknowledged this has a chance to provoke anxiety, and the autistic students reported how it was very difficult to think on the spot to provide an answer in front of everyone. This could be as a result of communication pressure, or needing extra time to process the question to be able to provide an answer, showing how executive functioning difficulties can overlap with communication difficulties (Torske, Nærland, Øie, Stenberg & Andreassen, 2018).

#### DISCUSSION OF ACCESS TO SUPPORT SERVICES FOR AUTISTIC STUDENTS

This was a large theme with several subthemes standing out. Mental health services in particular were a large focus of discussion, highlighting that this is one of the areas where provision and access could be better. Accessing mental health services is already difficult for typical university students, with students already facing significant physical and mental health challenges (Grasdalsmoen, Eriksen, Lønning & Sivertsen, 2020). As autistic people are more predisposed to developing depression and anxiety (Cleinmark et al., 2020) and are more likely to struggle accessing mental health support (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018). This means that the problems with their physical health due to factors like restricted diets (Folta et al., 2020), the issues accessing support that typical higher education students face may be increasingly worse for autistic students. Staff in this study admitted that they did not know how to help an autistic student who was struggling with mental health problems other than to send them to the university wellbeing services, but voiced frustration that they knew the wellbeing services were not adequately equipped to be able to provide efficient and effective support in crucial moments.

A lack in mental health services has shown to be a problem in universities where there is increased anxiety and stress for typical students globally (Asif, Muddassar, Shahzad, Raouf &

Pervaiz, 2020; Jenkins, Ducker, Gooding, James & Rutter-Eley, 2020; Lew et al., 2019). Suggestions in the focus groups were that staff could take mental first aid courses which have been proven effective in several areas as a systematic review shows mental health first aid training was successful in reducing the perceived stigma the trainees had of mental illness and increased the support and effectiveness of support for those receiving the support as well as improved confidence in helping someone with mental health support (Morgan, Ross & Reavley, 2018). These also were considered to be a good compromise between having to just send students to the support services where there would be long waiting lists, and if they did improve staff confidence, it could be worth trialling mental health first aid training in universities in future research to provide support not only for struggling autistic students but for all struggling students where support is difficult to access.

Difficulties asking for help are another key reason why support may be inaccessible to autistic people. Findings discussed in the literature review show that autistic people have difficulty asking for help across all fields including in school, help with their mental health, physical health and in employment (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018). The findings of this study show that universities are also places where it is thought that difficulties asking for help affect the service provision they receive. In terms of asking for support with their mental health or their studies, staff noted that autistic students rarely come to them for any sort of support until they are at breaking point, by which point they can only send them to an overwhelmed student wellbeing service despite being at crisis point and needing immediate help. Relying on autistic students to be proactive when it comes to seeking support leads to the staff feeling helpless, however the students in this study noted support systems were not set up in an autism-friendly way that would allow them to easily access and ask for help. When it comes to asking for help, autistic students are expected to make phone calls, which can provoke anxiety and which they may deliberately avoid doing if it makes them feel worse than they already do (Muller, Schuler, Burton & Yates, 2003). To make support systems more accessible, there should be strategies and solutions put in place to make it easier for autistic people to ask for help, perhaps future research looking at combining autistic students' communication preferences and incorporating that into the higher education mental health support that is already available.

Training is also available for autistic children that has had some success in raising their confidence in asking for help (Gillespie et al., 2017) and so a method such as this could be adapted and provided to the autistic students via the wellbeing services a higher education institution has.

Another large issue that the participants had with the support service provision in higher education is that it is disorganised and is not cohesive. *"One hand doesn't know what the other hand does"*. This shows that while support systems do exist, they may not always be working together to provide the holistic and person-centred support that has been shown to be beneficial to autistic people (Thompson, Bölte, Falkmer & Girdler, 2018). Participants in this study felt like a way to remedy this would be to have a service that evaluates the supports given to autistic students, and whether they met the needs of autistic students as well as typical students, and if the service was providing all the support it set out to achieve. Largely it was felt that support systems existed to just tick boxes and to say that the support existed within the university without having an evaluation of its effectiveness. Current research suggests that university mental health support for all students is lacking (Asif, Muddassar, Shahzad, Raouf & Pervaiz, 2020; Jenkins, Ducker, Gooding, James & Rutter-Eley, 2020; Lew et al., 2019), and in particular autistic students find it difficult to find consistent and cohesive support throughout higher education (Camm-Crosbie, Bradley, Shaw, Baron-Cohen & Cassidy, 2018).

#### DISCUSSION OF OVERWHELMED AND UNDERFUNDED SUPPORT SERVICES

Autistic students in this study said while they were aware of the support services, often they are overworked. This is generally the case not only in universities, but support services for autistic adults and children are fragmented and overwhelmed by numbers (Brewer, 2018). In previous research only 62% of autistic students received help, with some not receiving help even when asking for it (Gurbuz, Hanley & Riby, 2018). Staff were worried that the mental health support services in particular were overwhelmed by the numbers of students they send to them each year. In general, the UK's mental health services have suffered a lot of funding cuts and are expected to do the same amount or more for much less of a budget and staff, leading to poorer quality support (Cummins, 2018). If this is also the case with universities, as student numbers are increasing nationally but mental health services do not

seem to be expanding, then this will put significant pressure on the existing supports to do the same amount but for increasing numbers and with less of a budget.

A lack of NHS funding means that NHS mental healthcare is already becoming inaccessible (Cummins, 2018; Iacobucci, 2018), and with staff having no choice but to send students to the wellbeing service, they would become overwhelmed by the numbers that are struggling to get treatment from their GP or health service. The lack of availability of support could be another reason why autistic students are reluctant to ask for help, and is supported by previous research as autistic students were deterred by long waiting lists (Crane, Adams, Harper, Welch & Pellicano, 2018) and did not believe the help or support they could get would be beneficial to them (Gurbuz, Hanley & Riby, 2018). Better funding and an expansion of support services is needed to benefit autistic students and to make them feel like they would get sufficient help if they asked for it. It would also benefit all students with difficulties who need support, and so adapting universities to be able to provide more support for autistic students would not be detrimental to other students either.

#### DISCUSSION OF AUTISM AWARENESS WITHIN UNIVERSITIES

Overwhelmingly the participants in this study believed there was not enough autism awareness within universities in order for autistic students to be able to get the most out of their higher education. This shows that there are clear barriers to providing access, and that there is a lot of work that still needs to be done regarding improving both the awareness and understanding of autism in a higher education setting. The two subthemes found in this study cover both current understanding of autism and how this may not accurately represent those who are autistic, and how there is no helpful way of learning about autism for university staff.

Autism awareness is largely overlooked in universities, with plenty of staff and students alike holding false beliefs about autism such as stereotypes based on popular media such as *The Rain Man* and *The Good Doctor* depicting a socially awkward autistic genius (Huws & Jones, 2010; Conn & Bhugra, 2012; Zerbo, Massolo, Qian & Croen, 2015; Tharian et al., 2019) when most autistic people want people to know they are not like that at all (Botha, Dibb & Frost, 2020). Staff may also be more likely to believe autism is a condition that only affects males due to stereotypes held (Whitlock, Fulton, Lai, Pellicano & Mandy, 2020)



which may lead to autistic women having a lower quality of education as their struggles are dismissed or labelled as something else. Breaking stereotypes will help lift the expectations that are put on autistic students; how people expect them to behave and react in any given situation and the types of things that autistic people are good or bad at academically. While staff were aware that the stereotypes did not necessarily reflect autistic people but recognised that a lot of people would place expectations on autistic students based on stereotypes, which is supported by prior research (Zerbo, Massolo, Qian & Croen, 2015). To reduce perceived stereotypes and stigma around autism more exposure is needed, which could be done through the media and help people familiarise themselves with autism (Mitchell & Locke, 2014), or the option to have online training (Gillespie-Lynch et al., 2015) which could reduce the stigma and reduce stereotyping.

Students in this study said that autism was not acknowledged within the university at all, which could end up leading to staff not even realising they could be making adaptations to provide an easier learning experience for some of their cohort. This could be a factor in autism's reputation as a 'hidden' disability, and people need to become aware of it within a university context in order to be able to provide the correct support and adaptations (Grinker, 2020). Staff currently have to rely on their own knowledge and experience of autism in order to decide what is best practice for autistic students as is shown in this study and other qualitative studies examining the experiences of autistic students (Cage & Howes, 2020) and this may not provide effective support and could lead to an increased chance of dropping out and not completing their education.

Staff were not aware of any useful training they could go to regarding autism, and while such training does exist for providers in other fields such as primary and secondary education (Alexander, Ayres & Smith, 2014) staff within universities are not offered it, and have to be proactive in seeking anything out. The implications of this are that staff are having to provide for a neurodiverse cohort with very little understanding of their diverse range of needs, as autistic students will require different supports to neurotypical students, which could significantly impact on just how useful the contact hours are to the autistic students. Furthermore, the current guidelines that staff can find on the National Autistic Society website reportedly go against what they are told is engaging teaching, so staff are left with a decision to try to provide engaging teaching for the majority, or to cater to the

needs of autistic students. More must be done to find a balance in teaching supports and styles that benefits everyone.

### DISCUSSION OF TRANSITION TO UNIVERSITY

Transitioning to university is a challenging time for all students (Lei, Ashwin, Brosnan & Russell, 2019) with staff in this study saying how no student is ever fully prepared. However, with difficulties adapting to new environments and situations (Alverson, Lindstrom & Hirano, 2015; Lei, Ashwin, Brosnan & Russell, 2019) it is agreed that transition to university will disproportionately have an impact on autistic students compared to their peers. Staff predicted that this area would be one of the key areas that autistic students would struggle with the most.

In particular it was living in student accommodation that all participants highlighted as a key area in this study. Living alone and independently is a challenge for autistic students as they will be leaving their established support systems and routines behind (Lambe et al., 2018) to living with strangers which could provoke large amounts of anxiety (Alverson, Lindstrom & Hirano, 2015). An autistic person taking part in this study was assaulted while living in student accommodation, and as autistic people are more likely to be at risk of assault and violence (Griffiths et al., 2019) more needs to be done to safeguard autistic students moving to university. The living arrangements cause anxiety and a feeling of their bedroom being their living space, not including the rest of their halls. Autistic students typically have a harder time adapting to university accommodation and university life than autistic students who go to university while still living at home (Lambe et al., 2018) which was also brought up in this study as a known issue for autistic students, suggesting that there should be more support for autistic students who move to university establish routines and support networks. More needs to be done to support the autistic student population who live away from home, and to ensure that support networks are established to replace the ones they leave behind.

Universities that engage with autistic students beforehand typically see a higher success rate of autistic people adapting to their new surroundings and situations, with less anxiety and a better adaptation to the new routines university brings (Lei, Calley, Brosnan, Ashwin & Russell, 2018). Research shows this is effective at easing anxiety and easing autistic students

into university life before the income of the new typical student population, however it is not mandatory for all universities to do this, and so as not to limit autistic students' university choices by the support available, more research could be done into the feasibility of making this a requirement for all higher education settings to follow.

Going by the staff and student identified barriers in this study, living away from home for the first time appears to be a barrier regarded of high challenge and high importance to tackle. Research looking in the direction of transition to university for autistic students could tackle the feasibility of implementing a system that allows autistic students to transition to university beforehand, and implementing it in a way that is accessible to all universities regardless of their budgets for student support. Tackling this issue may make transition easier for autistic students, and if done well transition may no longer be identified as a key issue to autistic students regarding their higher education experiences. As it stands, staff and students identified living away from home as a barrier to making the most out of higher education, showing there are still significant perceived difficulties to tackle.

#### LIMITATIONS AND DIRECTIONS FOR FUTURE RESEARCH

Due to the lengthy delays of the ethics processes to get this research ethically approved, participant recruitment was taken during a time when most students were no longer at the university for the year, so the small sample size for this study is acknowledged. Despite this, a good amount of data was gathered centred around a good discussion, and it would provide a good basis and direction for future research in other universities. The participants were from diverse roles in the university, gaining a wide range of staff perspectives on barriers to higher education for autistic students, unlike most studies in this area that focus on research staff. This way we were able to gain perspectives from those in technical roles in the university and in non-student facing roles and were able to gain differing opinions on how any form of training should be rolled out. A larger sample size could potentially be gained by holding the focus groups at different universities with a larger autistic student population, or by holding focus groups earlier in the year at a time which is not around any student holidays, or exams and deadlines. Research has been conducted with small sample sizes before of only 14 participants (Cage & Howes, 2020), but to improve upon this research in the future there could be more focus groups with more participants from each

of the diverse roles contacted for this study, and more autistic staff and students involved. Another barrier to gaining more autistic students for this study is that many autistic students are unwilling to disclose their diagnoses (Mary Rose, Burke, Quinn & Harris, 2019), and so recruitment materials could be adapted to reassure any participants that their diagnosis would not be reported anywhere else but this research.

Collecting only qualitative data has given this research in depth higher education specific insights which has led to a deeper in-depth discussion which has been analysed for emotional responses. Due to the heterogeneity of autism and how experiences are so varied between autistic students and between staff, the decision to collect qualitative data was made. It captures perspectives about the situations as well as barriers autistic students could find distressing, however, results like this will be difficult to replicate due to the personal nature of the experiences of the staff and students involved. Their experiences will not be the same as other staff or autistic people within the universities included in this research or other higher education institutions across the UK, and thus cannot be generalised beyond the population of this study. To improve on this, research such as this could be carried out at different higher education institutions across the UK to see if similar themes in thematic analysis emerge and if similar suggestions for improvement to the higher education systems are raised. Quantitative studies could also be based on the results of this research to test whether any of the key findings are generalisable to other higher education institutions, to give an insight into the highest priorities to address in terms of barriers to higher education in the UK.

Another limitation of this research is that as autistic students' experiences differ enormously; qualitative data has no way of finding statistically common ground between the struggles and difficulties autistic students in higher education students face as a whole and has no way of identifying which issues are more common than others. Further research should be done on a more widespread scale across many different universities based on the findings of this research. Such as, the things autistic students have found difficult, whether they are common issues not only in this research sample but across many autistic student samples within the UK and whether the suggestions posed by both staff and students in this research would be helpful at only the University of Lincoln and Bishops Grosseteste University, or whether they should be considered for implementation through all higher

education institutes in the UK. There is also very little data within this research on supports within other higher education institutions across the UK, relying on the experience of other universities the staff had in the focus group to provide insight. More information would need to be gathered to establish what the standard base line of support is for autistic students across the UK, and what support staff in those institutions feel they may benefit from.

There was much criticism of the systems in place in higher education to support autistic students and many suggestions to improve upon these and remove all the barriers to accessing higher education. However, due to having two separate focus groups, one for staff and one for autistic students, there was no room for discussion as to whether autistic students would find the suggestions staff made useful, or as to whether staff would find the suggestions made by autistic students feasible to implement in higher education settings. There was also no means of comparing views during discussions in focus groups, or for autistic students and staff to discuss their experiences and opinions on autism, which could have been an enlightening and beneficial experience for both groups. The decision to use focus groups though, fostered discussion and agreement amongst the groups about the primary issues and barriers facing autistic students and allowed the participants to challenge each other's' thinking, allowing for a level of thought and discussion that would not have been achieved using interviews alone, and therefore is a strength of this study over an individual interviews methodology used in a lot of previous literature.

Further limitations to this study include the choice to use thematic analysis, which is not completely free from researcher bias. The primary researcher is also autistic which may have biased the results and interpretation of this study. Despite the potential for bias, this could add to the clarification and interpretation of any data gathered from autistic staff and students who took part in the study, with less of a communication barrier. However, steps were taken to reduce as much researcher bias as possible; there was a second researcher in the focus groups to ensure biased and leading questions were not asked by the primary researcher, with a copy of the agenda of the focus groups with questions that has been checked by two other members of the research team for any leading questions or language. Potential researcher bias is a large flaw of this study, despite the data being re-evaluated and reanalysed by the research teams to try and limit confirmation bias, and if this research

were to be done again, a different non-autistic member of the research team would be asked to do the coding of the data, with another member of the team checking and interrater reliability. As the primary researcher was autistic, there may have been researcher bias, but the findings from the study may have also been interpreted more accurately than if a neurotypical researcher had been the primary data analyst due to the communication differences between autistic and neurotypical people. Therefore, the analysis of the data may more accurately reflect the meaning of the discussions in the focus groups.

Participant confirmation bias could also have influenced this study's results, as all participants were informed to the purpose of this study beforehand and that they would be discussing their perceived barriers to education for autistic students. This means that by taking part in this study, they might have felt it necessary to say that they saw barriers where they did not due to the social desirability bias and the want to say something the rest of the group would agree with. To avoid this in future research, each participant could be interviewed individually, with questions carefully phrased to avoid leading language and to make the participant feel accepted whether they had or had not noticed any barriers to autistic students' higher education.

A further limitation of this research is that it is difficult to examine any causality of the issues found in this research. While it is clear from the data that staff and students are aware of barriers to autistic students in higher education, the causes and nuances of these barriers cannot be established or commented on in greater detail without further research. To make any meaningful suggestions from this data it would have to be backed up by prior research, or used as the grounds to establish future research. This could end up looking at one of the issues in greater detail to establish any causes, how widespread the issue is as opposed to the limited generalisability of the focus groups, and the efficacy of any suggestions made by the participants of this study.

Future research that could come from this study could be quantitative research based around each of the themes found. Executive functioning difficulties could be quantified in terms of how many autistic students are late to lectures and seminars and hand things later as opposed to the rest of the student population, or percentages of autistic people who say

they struggle and suffer from anxiety if their daily routines are disrupted or changed by irregular teaching. Help to information processing issues could be tested by looking into just how helpful things like slide numbers, allowing access to teaching material beforehand and subtitles on videos are. The suggestions given by staff and students, while having very little merit without the research to back them up, could lead to research testing them and lead to smaller interventions and changes that could help. Sensory difficulties for autistic students could be further understood by looking into the types of stimuli people in this study have identified as potentially distressing such as the use of videos in lectures and the design of the lecture theatres being uncomfortable. Identifying the types of stimuli that are most distressing to autistic students in university settings could then lead to strategies to make higher education more accessible to those with different sensory needs to typically developing students. Further research could be done to evaluate whether any social skills training used in other fields is effective for autistic students in university, and an evaluation of how feasible it would be to provide this with university resources, and who would be responsible for it. A thorough evaluation should be done of university support services for autistic students, the typical student population and a comparison seen between the two, as lots of issues highlighted in this research regarding accessibility such as the increasing demand for mental health support will affect all students. One way to increase autism awareness in universities would be for an autistic-lead training program to be developed, using participatory research methodology to involve autistic students in developing and testing an autism awareness and acceptance training course to deliver to staff, addressing issues like stereotypes, perceived and acted stigma, and misconceptions about autism. Further research could also be done to ease the stressful perceived barrier of transitioning to university such as testing any existing early transition periods for autistic students and getting autistic students to evaluate them and comment on what could be improved, implementing the improvements and testing them again, and then implementing this in as many higher education institutions possible.

The results of this research while not substantial enough to make recommendations on its own, could provide the basis for future research such as this, and has highlighted some important perceived barriers that could be investigated in further detail, and that could be

highlighted as a priority for future applied research looking at supports for autistic people trying to access higher education.

## CONCLUSION

This research set out to examine perceived barriers to autistic students in higher education and reached its aims by interviewing both staff and autistic students in focus groups on the barriers they think autistic students face, and what could potentially be done about this. Findings show there could be many barriers to autistic students trying to access higher education that may be similar with difficulties already faced in trying to access primary and secondary education, physical healthcare, mental healthcare and employment, as well as the findings being supported by previous literature (REFS).

Staff have a lack of knowledge on autism consistent with previous literature (REFS) though in this study there was shown to be understanding that autistic students will not be like the stereotypes in the media. This suggests that while staff have been getting their exposure to autism through the media and through their personal experiences, there is more awareness and knowledge around the falsehoods of stereotypes now than seen in previous research (Gillespie-Lynch et al., 2015). This shows hope that with the correct training program, university staff could develop more autism awareness and acceptance, which would go a large way to making higher education more accessible to autistic people. Despite this, participants in this study overwhelmingly all agreed there was not enough autism awareness in universities, and so this indicates that more research should be done into just how much university staff understand about autism as well as any misconceptions they have, such as the research done into attitudes to autism and autistic students from typically developing university students (Zerbo, Massolo, Qian & Croen, 2015). This research could further the drive to find out exactly how much of a barrier a lack of autism awareness and acceptance is to autistic students, and the drive to find effective ways to remove this factor as a barrier.

Service access appeared to be a key concern for autistic students, suggesting that the services are not equipped to deal with the capacity of students within higher education, and that the supports they provide are inadequate and ineffective. Staff suggest this is because there is no coordinating body between the systems of support including academic and mental health support, that there is no independent organisation to critically evaluate the



effectiveness of support a higher education institution provides. This shows there is perceived room for improvement on how universities provide both academic and mental health support to their autistic students, who are already at a higher chance of developing co-occurring conditions such as anxiety and depression even outside the stresses of an academic environment (Hollocks, Lerh, Magiati, Meiser-Stedman & Brugha, 2018). It can be suggested that due to the risk to autistic people's mental health, further research into service provision and supports should be a high priority for future research.

Uncertainties in this research could come from the small sample size, and the choice to use only qualitative data rather than a mixed methods approach. This could lead on to more research with a wider sample of participating universities in order to see if the same themes found in the thematic analysis of the transcripts in this research would also be found in other universities across the UK. There could also be the potential for quantitative research in this area looking at whether these experiences are common on a wider scale across the UK and whether suggestions from this research would be helpful in other higher education institutions. If this research were to be conducted again, a mixed methods approach would be used in the same style of the AIMS-2-TRIALS 10 Points Study which is still in progress (Gibbs et al., 2021), with an initial PPI focus groups to determine priority areas for autistic students and staff within higher education combined with a thorough literature review to pick out key points. Then a survey would be built to collect data about autistic people and staff's experiences in each of these priority points before asking them to rank them in order of how important they are to them.

This research set out with the intention to identify perspectives of barriers to autistic students in higher education. Thematic analysis of focus group transcripts with staff and students, has identified key areas that autistic students struggle in, consistent with previous literature and that overlap with the barriers to different services in different fields such as employment (Remington & Pellicano, 2018), healthcare and mental healthcare (South & Rodgers, 2017) and primary and secondary education provided (Dillenburger, McKerr, Jordan & Keenan, 2016) such as executive functioning (Ryan & Marshall, 2018) and sensory difficulties (Mason et al., 2019). It has also gone further than identifying barriers as participants were keen to suggest ways of removing the barriers and difficulties identified, which shows promise for research into more community created interventions and

improvements in universities if staff and autistic students were given the option of coming together and discussing what they could improve. Data collected could help highlight priority areas for research due to the identification of barriers by staff and students, highlighted areas that need improvement. This could then go on to inform future research, and to inform funding bodies of the priorities when it comes to alleviating barriers to autistic students in higher education. More issues were identified that would need the intervention of more authoritative university staff. It also provides as a good foundation for more research in this area on a larger scale and serves as a good directional piece for any future research.

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## **Appendices**

### **Appendix A**

#### **Participant Information Sheet/Information about the research (Draft Version 0.4 / Final version 1.0: 7/4/19)**

**DO NOT change the font, size or formatting of the template**

**Title of Study: Identifying barriers faced by autistic people in higher education**

**Name of Researcher(s):** Kathryn Gibbs

We'd like to invite you to take part in our research study. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through this information sheet with you, to help you decide whether or not you would like to take part and answer any

questions you may have. We'd suggest this should take about 15 minutes. Please feel free to talk to others about the study if you wish.

### **What is the purpose of the study?**

This research is a part of my Master's thesis for my degree in MSc psychology by research.

The data will be used as a part of my Master's thesis, and also the themes found will be used in creation of an autism awareness and intervention training program to be given to staff.

### **What?**

This study aims to identify key barriers autistic people face in higher education, to analyse the data for themes and to use that data to create a training program on autism awareness and understanding to be given to staff at the university.

By doing this research we hope to create a training program that is tailored to the specific needs and barriers identified in these focus groups, which will hopefully alleviate some of the issues raised and improve the lives of autistic people within higher education settings.

### **Where?**

Both focus groups will take part within a room booked within the university

### **Why have I been invited?**

You are being invited to take part because you would fit into one of two focus groups we are running; one consisting of autistic students at the university, and one consisting of staff members within the university. No expert knowledge of autism is required to take part.

We are inviting 20 participants like you to take part, 10 autistic students in one focus group, 10 university staff members in the other.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

### **What will happen to me if I take part?**

You will be asked some open ended questions regarding your experiences and prompted into a discussion with the other participants. Discussions will be audio recorded and transcribed after the focus group has ended. All personally identifiable data will be redacted and data shall remain anonymous.

The focus groups should last no longer than an hour and a half and you are free to withdraw and leave at any time. Focus group sessions will be held in the university building.

### **Expenses and payments**

Participants will not be paid (to participate in the study. Students signing up on the SONA system however will receive 6 credit points for participation

### **What are the possible disadvantages and risks of taking part?**

We do not anticipate that there are any risks with this study, however if you have any concerns please do not hesitate to email one of the researchers or speak to us in person before or after the focus group takes place.

### **What are the possible benefits of taking part?**

If you are a psychology student you are eligible to receive 6 SONA credit points. By taking part in this research you are helping to create a training program for autism awareness and understanding to be used by university staff, to improve the university experience of autistic students

### **Will my taking part in the study be kept confidential?**

We will follow ethical and legal practice and all information about you will be handled in confidence. Although what you say in the focus group is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

### **Privacy notice**

The University of Lincoln is the lead organisation for this study. The university's Research Participant Privacy notice <https://ethics.lincoln.ac.uk/research-privacy-notice/> will explain how we will be using information from you in order to undertake this study and will be the data controller for this study. This means that we are responsible for looking after your information and using it properly.

We will keep identifiable information about you for 5 months after the study is complete

### **What will happen if I don't want to carry on with the study?**

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw from the study, we will keep the information about you that we have already obtained unless you decide to withdraw your data. To safeguard your rights, we will use the minimum personally-identifiable information possible.

### **What will happen to the results of the research study?**

Data will be treated confidentially and all names in any data will be redacted along with any other personally identifiable information. The anonymised dataset however may be shared with other researchers or made available in online data repositories. The data will be analysed alongside other data sets and individual responses will not be examined. The results will also be written up as part of an MSc thesis.

### **Who is organising and funding the research?**

This research is being organised by the University of Lincoln

### **Who has reviewed the study?**

This study has been reviewed and given favourable opinion by Lincoln Research Ethics Committee.



### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting [ethics@lincoln.ac.uk](mailto:ethics@lincoln.ac.uk).

If you feel that we have let you down in relation to your information rights then please contact the Information Compliance team by email on [compliance@lincoln.ac.uk](mailto:compliance@lincoln.ac.uk) or by post at Information Compliance, Secretariat, University of Lincoln, Brayford Pool, Lincoln, LN6 7TS.

You can also make complaints directly to the Information Commissioner's Office (ICO). The ICO is the independent authority upholding information rights for the UK. Their website is [ico.org.uk](http://ico.org.uk) and their telephone helpline number is 0303 123 1113.

### **Further information and contact details**

Primary researcher

Kathryn Gibbs - [KGibbs@lincoln.ac.uk](mailto:KGibbs@lincoln.ac.uk)

Supervisors

Niko Kargas - [NKargas@lincoln.ac.uk](mailto:NKargas@lincoln.ac.uk)

Stefano Belli - [SBelli@lincoln.ac.uk](mailto:SBelli@lincoln.ac.uk)

### Appendix B

Project ID: [29-MAR-0323](#)

Participant ID for this study (participant copy only):

## **CONSENT FORM**

*(Version 4, 26/4/19)*

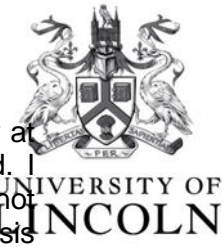
**Title of Project: Identifying barriers faced by autistic students in higher education**

**Name of Researcher: Kathryn Gibbs**

**Name of Participant:**

Please  
initial  
box

1. I confirm that I have read the information sheet dated [26/4/19](#) (version [4](#)) for the above study. I have had the opportunity to consider the information, ask questions and have  
had these answered satisfactorily.



2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. I understand that should I withdraw then the information collected so far may not be erased, and that this information may still be used in the project analysis unless I also choose to withdraw my data.

3. I understand that relevant sections of data collected during the study, may be looked at by individuals from the University of Lincoln, from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records, I understand that my personal details will be kept confidential.

4. I would like to receive a summary of the results of the study Yes  No   
 (We will store your email on the University OneDrive until a summary can be sent if you agree)

5. I agree to take part in the above study.

|                               |       |           |
|-------------------------------|-------|-----------|
| _____                         | _____ | _____     |
| Name of Participant           | Date  | Signature |
| _____                         | _____ | _____     |
| Name of Person taking consent | Date  | Signature |

Appendix C:

**Participant Debrief Sheet**  
 (Draft Version 0.3 / Final version 1.0: 29<sup>th</sup> March)

**DO NOT change the font, size or formatting of the template**

**Title of Study:** Identifying barriers faced by autistic students in higher education

**Name of Researcher(s):** Kathryn Gibbs

**Contact Details of the Researcher(s) are given at the end.**

We'd like to thank you for taking part in our research study. This research will provide crucial information and broaden our understanding of the issues and barriers faced by autistic students in higher education, and to enable possible solutions for them.

**What was the aim of the study?**

Firstly I would like to thank you for taking part in this focus group. As detailed in the participant information form you are free to withdraw your data for two weeks by contacting the researchers. This study has been aiming to identify key barriers autistic students face in higher education and your data will be analysed and then go on to create a training program to give to staff which will improve the lives of autistic students in university.

### **Questions and withdrawing**

If you have any further questions about the study, please feel free to ask the researcher before you finish or alternatively contact the researcher or their supervisor at any time on [KGibbs@lincoln.ac.uk](mailto:KGibbs@lincoln.ac.uk) or [NKargas@lincoln.ac.uk](mailto:NKargas@lincoln.ac.uk). If you wish to withdraw your data please also contact the researcher or supervisor on [KGibbs@lincoln.ac.uk](mailto:KGibbs@lincoln.ac.uk) with your unique participant number. In cases where your participation was anonymous please contact [ethics@lincoln.ac.uk](mailto:ethics@lincoln.ac.uk) with your unique participant number. Please note you will only be able to withdraw up until the point of data analysis.

### **Further help and support**

If you have any ethical concerns regarding the current research, your treatment as a participant or your involvement in the study please feel free to contact [ethics@lincoln.ac.uk](mailto:ethics@lincoln.ac.uk).

If you have been affected by any of the issues raised by taking part in this study the following organisations may be able to provide help and advice:

seek advice from your GP

or contact the Student Wellbeing Centre on 01522 886400 or [studentwellbeing@lincoln.ac.uk](mailto:studentwellbeing@lincoln.ac.uk) where you can seek counsel should you wish to discuss any issues that may have arisen from your participation

### Appendix D

#### **Focus group questions**

##### **For the autistic students focus group - facilitated by student researcher**

-transition to uni

- How did you find your transition to university?

- social and communication skills

- how do you find communicating with peers and staff at university?

- disclosure of diagnosis/ ASD awareness

- Have you disclosed your diagnosis to the university?

- do you think staff in the university are aware and understanding of the autistic students?

sensory processing issues

- Do you have any sensory sensitivities? In what way do they affect your university experience?

-daily living

- What is your daily university routine, what do you find easy or difficult about it?

- support service access and usefulness

- Are you aware of the services available for autistic students?

- what services need improving/providing and how?

- Is there anything else you would like to cover?

**Focus group for university staff -**

- ASD awareness and awareness of autistic students

- Do you think the university is accommodating to autistic students?

- Do you think staff know enough about autism?

- Autistic students transition to university

- Do you think autistic students are prepared enough for university?

- Autistic students' social and communication skills

- What do you think you would need to know to get better at communication with autistic students?

- what different challenges do you think lectures and seminars present to autistic students?

- Emotional difficulties and comorbid conditions

- would you be confident in dealing with an autistic student who asked for help regarding the university's mental health services, what do you think may be the reasons for that?

- Sensory processing issues ASD students may have

- Based on your experience if you met an autistic person with sensory sensitivities how would you alter your practice?


-Support services in place for autistic students

-Would you know what services to recommend to autistic students?

- what preparations and measures to you think the university should take to be more accommodating?

- Is there anything else you would like to discuss?

## Appendix E



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LINCOLN

**Application Details**

Ethics Reference 2019-Mar-0323

Title of Project Identifying barriers faced by autistic students in higher education

Lead Researcher Kathryn Gibbs

Academic Supervisor Niko Kargas, Stefano Belli

Committee Human Ethics Committee (PR)

Date of Ethical Opinion 5 April 2019

**Favourable Opinion**

Thank you for your revised submission. The further information has been considered on behalf of the committee and I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form.

The favourable ethical opinion provided is conditional to the following requirements:

- The following must be added to any recruitment materials: including posters, adverts, social media posts "The project [insert study title] contributes to research conducted on behalf of the University of Lincoln and has received a favourable ethical opinion by a University Research Ethics Committee (insert Ethics Reference - given at the top of this letter) in accordance with the Guidelines for research recruitment materials (available on the ethics portal page).
- A reviewer comments that the following statement may be somewhat leading: "This will be used to improve understanding of autism, and help staff amend their practice to become more autism-friendly". The reviewer was concerned that this was a bit leading i.e. suggesting that staff's practice isn't autism friendly. What about 'improve' or 'enhance' their current practice? If you decide to amend your poster in light of this, please submit your revised poster to ethics@lincoln.ac.uk

**1. Commencement of the research**

1.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

1.2 If the research does not commence within 12 months of the favourable opinion being issued, the lead applicant (and academic supervisor for student research) should send a written explanation for the delay. A further written explanation should be sent after 24 months if the research has still not commenced.

1.3 If the research does not commence within 24 months, the REC may review its opinion.

**2. Duration of favourable opinion**

2.1 The favourable ethical opinion of the REC for a specific research study applies for the duration of the study, as detailed in your application (or any subsequent amendments).

**3. Amendments**

3.1 If it is proposed to make an amendment to the research, the lead applicant (authorised by the academic supervisor) should submit an amendment to the REC by accessing the original application form on LEAS and creating an amendment form.

**4. Monitoring**

4.1 Research Ethics Committees may review a favourable opinion in the light of progress reports and any developments relevant to the study. The lead applicant and academic supervisor for student research, is responsible for ensuring the research remains scientifically sound, safe, ethical, legal and feasible throughout its duration. The lead applicant and academic supervisor for student research should submit a progress report to the REC 13 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be completed and submitted using the forms in LEAS.

**5. Conclusion or early termination of the research**


5.1 The Lead Applicant should complete the End of Study Form in LEAS once the study has completed. It is also their responsibility to inform the Committee of early termination of the project or if the work is not completed.

**6. Long Term Studies**

The lead applicant and academic supervisor for student research is responsible for ensuring that the study procedures and documentation are updated in light of legislative or policy changes and also for reasons of good practice (e.g. standards for supporting documentation). This should be documented in the progress report to the REC (see above) and, where necessary, an amendment (see above) should be submitted to the REC. The REC may review its opinion in light of legislative changes or other relevant developments.

Additional guidance may be found at [here](#)

Yours Sincerely



Dr Amanda Roberts  
Deputy Chair – Human Research Ethics Committee

## Appendix F: NVivo Analysis

### Initial final codes

| Nodes  |       | Search Project |                  |            |                  |             |  |
|--|-------|----------------|------------------|------------|------------------|-------------|--|
| Name   | Files | References     | Created On       | Created By | Modified On      | Modified By |  |
| THEME 1 - NO INFO GIVEN TO STAFF ABOUT STUDENTS              |       | 0              | 05/08/2019 18:25 | KG         | 07/08/2019 16:37 | KG          |  |
| THEME 2 - AUTISM AWARENESS IN UNIVERSITIES                   |       | 0              | 05/08/2019 18:26 | KG         | 07/08/2019 16:54 | KG          |  |
| THEME 3 - INNEFFECTIVE AND DIFFCULT TO ACCESS SUPPORT        |       | 0              | 05/08/2019 18:26 | KG         | 09/08/2019 12:51 | KG          |  |
| THEME 4 - UNIVERSITIES NOT ACCOMODATING TO AUTISTIC STUDENTS |       | 0              | 09/08/2019 13:13 | KG         | 10/08/2019 14:56 | KG          |  |
| THEME 5 - SUGGESTED IMPROVEMENTS TO UNIVERSITIES             |       | 0              | 10/08/2019 10:33 | KG         | 10/08/2019 10:37 | KG          |  |
| THEME 6 - COMMUNICATION CHALLENGES                           |       | 0              | 10/08/2019 11:16 | KG         | 10/08/2019 11:16 | KG          |  |
| THEME 7 - TRANSITION TO AND LIVING AT UNIVERSITY             |       | 0              | 10/08/2019 14:52 | KG         | 10/08/2019 14:52 | KG          |  |

## Final themes after consultation with research team

| Nodes   |       |            |            |                  |             |                  |   | Search Project |
|---|-------|------------|------------|------------------|-------------|------------------|---|----------------|
| Name  | Files | References | Created On | Created By       | Modified On | Modified By      |   |                |
| EXECUTIVE functioning difficulties can affect access to university life |       | 2          | 18         | 13/09/2020 18:20 | K           | 13/09/2020 18:22 | K |                |
| SENSORY sensitivities cause barriers to education                       |       | 2          | 11         | 13/09/2020 18:20 | K           | 13/09/2020 18:21 | K |                |
| SOCIAL difficulties can make university stressful and difficult         |       | 2          | 18         | 13/09/2020 18:23 | K           | 13/09/2020 18:23 | K |                |
| SUPPORT services are difficult to access for autistic students          |       | 2          | 46         | 13/09/2020 18:12 | K           | 13/09/2020 18:12 | K |                |
| THERE is very little autism awareness within universities               |       | 2          | 27         | 13/09/2020 18:15 | K           | 13/09/2020 18:15 | K |                |
| TRANSITIONING to university can be a challenge for autistic students    |       | 2          | 12         | 13/09/2020 18:33 | K           | 13/09/2020 18:33 | K |                |

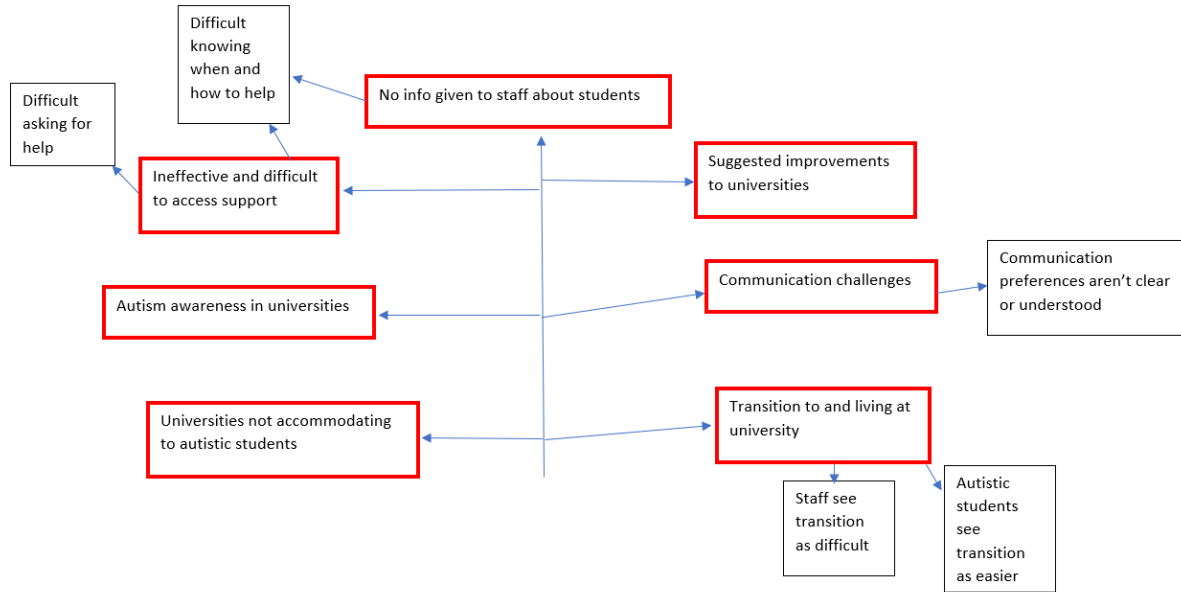
## Coding the transcripts

|  |   |   |                  |   |                  |   |
|--|---|---|------------------|---|------------------|---|
| Autistic students find it helpful when material for lectures and seminars is provided beforehand | 1 | 1 | 12/09/2020 23:28 | K | 12/09/2020 23:28 | K |
| Examples of assignments being provided beforehand can ease confusion about what                  | 1 | 1 | 12/09/2020 23:32 | K | 12/09/2020 23:32 | K |
| Exams that ask for very specific information within an essay are the most difficult due          | 1 | 3 | 12/09/2020 22:21 | K | 12/09/2020 22:24 | K |
| Giving students information beforehand to help them process it is useful and should              | 1 | 1 | 13/09/2020 17:51 | K | 13/09/2020 17:51 | K |
| Having a good schedule is important for being able to study. If the schedule is not good         | 1 | 1 | 12/09/2020 22:48 | K | 12/09/2020 22:48 | K |
| Having assignments due on the same day can cause difficulties with time management               | 1 | 1 | 12/09/2020 23:33 | K | 12/09/2020 23:33 | K |
| Irregular university schedules that broke routines became a problem                              | 1 | 1 | 12/09/2020 22:47 | K | 12/09/2020 22:47 | K |
| Seminars are unpredictable, and the prospect of being made to work with strangers is             | 1 | 2 | 12/09/2020 23:23 | K | 12/09/2020 23:25 | K |
| Seminars that allow preparation beforehand are useful, seminars that are vague and               | 1 | 2 | 12/09/2020 23:24 | K | 12/09/2020 23:27 | K |
| Slide numbers on powerpoints in lectures would be extremely helpful                              | 1 | 2 | 12/09/2020 22:32 | K | 12/09/2020 22:33 | K |
| Subtitles on videos in lectures would be helpful   | 1 | 1 | 12/09/2020 22:32 | K | 12/09/2020 22:32 | K |
| The best lectures are clearly structured and have breaks during them                             | 1 | 1 | 12/09/2020 23:38 | K | 12/09/2020 23:38 | K |
| The easiest exams are the ones where the information requires a logical system such              | 1 | 1 | 12/09/2020 22:23 | K | 12/09/2020 22:23 | K |

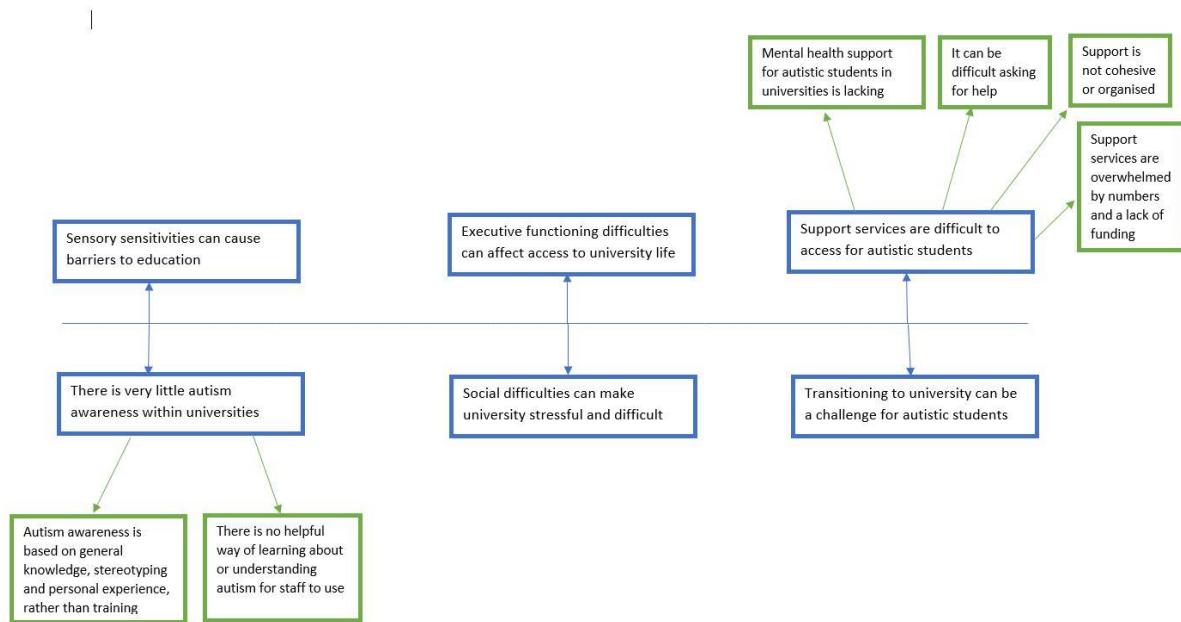
## Sorting into subthemes

|   |   |    |                  |   |                  |   |
|---|---|----|------------------|---|------------------|---|
| SUPPORT services are difficult to access for autistic students                              | 2 | 46 | 13/09/2020 18:12 | K | 13/09/2020 18:12 | K |
| A person centred needs model would be better at helping autistic people than relying        | 1 | 1  | 13/09/2020 14:14 | K | 13/09/2020 14:14 | K |
| Differing schools within universities have different systems around giving support. It      | 1 | 1  | 13/09/2020 14:21 | K | 13/09/2020 14:21 | K |
| If every lecturer has to provide the individual support for each autistic student, it would | 1 | 4  | 13/09/2020 14:18 | K | 13/09/2020 16:57 | K |
| Individualised support such as mentoring can be effective for autistic students, but taking | 1 | 2  | 13/09/2020 15:10 | K | 13/09/2020 18:04 | K |
| IT can be difficult to ask for help   | 2 | 5  | 13/09/2020 22:43 | K | 13/09/2020 22:43 | K |
| MENTAL health support for autistic students in universities is lacking                      | 2 | 9  | 13/09/2020 18:10 | K | 13/09/2020 18:11 | K |
| Neither lecturers nor autistic students get much information communicated to them           | 1 | 2  | 13/09/2020 12:58 | K | 13/09/2020 12:59 | K |
| Services are not easy to access, and a few missed sessions can result in a discharge from   | 1 | 1  | 12/09/2020 23:31 | K | 12/09/2020 23:31 | K |
| Some help, like extensions are being made more difficult to get                             | 1 | 1  | 12/09/2020 23:35 | K | 12/09/2020 23:35 | K |
| Staff cannot do anything for any problems other than academic problems                      | 1 | 1  | 13/09/2020 17:32 | K | 13/09/2020 17:32 | K |
| Students request support occasionally for lectures that lecturers had never even considered | 1 | 1  | 13/09/2020 17:56 | K | 13/09/2020 17:56 | K |
| SUPPORT is not cohesive or organised  | 1 | 8  | 13/09/2020 22:46 | K | 13/09/2020 22:46 | K |
| SUPPORT services are overwhelmed by numbers and a lack of funding                           | 2 | 10 | 13/09/2020 22:40 | K | 13/09/2020 22:41 | K |

## Initial themes thematic map



Final themes and subthemes thematic map



Appendix G

Attached document containing Nodes from the thematic analysis, named 'Nodes for perceived barriers to autistic students'

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