

HURDLES AND DRIVERS AFFECTING AUTISTIC STUDENTS' HIGHER EDUCATION EXPERIENCE: LESSONS LEARNT FROM THE MULTINATIONAL AUTISM&UNI RESEARCH STUDY

Marc Fabri, Penny C.S. Andrews

{m.fabri, p.c.andrews}@leedsbeckett.ac.uk
Leeds Beckett University (UNITED KINGDOM)

Abstract

Autism&Uni is an EU-funded project which aims to support greater numbers of young adults on the autism spectrum to gain access to HE and to navigate the transition successfully. This paper reports on the research done as part of the project, specifically an in-depth literature review and a multinational mapping survey in five European countries. The research focused on identifying the hurdles autistic students encountered as well as the drivers that can help them overcome the challenges they face. Universal Design for Learning is put forward as an approach that can potentially alleviate many of the difficulties encountered by autistic students whilst benefiting the entire student population, with all its diversity.

Keywords: autism, disability support, diversity, inclusion, universal design

1 INTRODUCTION

Autism is a lifelong developmental condition that affects how a person communicates with and relates to other people, and to the world around them. It is also a spectrum condition, which means that it affects different people in different ways. It is estimated that around 1 in 100 people are autistic [1]. A substantial proportion of autistic people is of average or advanced intellectual abilities and academically competent (often referred to as higher-functioning autism or Asperger Syndrome), although some have an additional learning disability [2].

Autism can lead to ways of thinking and behaving that appear unnecessarily rigid or repetitive, difficulties in understanding social interactions, and to difficulties in concentrating and processing information in typical ways. Many autistic people have specific strengths such as an ability to maintain intense focus, to adopt unconventional angles in problem-solving, or to spot errors that others may overlook. The strengths of autistic people as professionals in certain fields are increasingly recognised by businesses world-wide.

Although autism is not a predictor for academic success, autistic people are generally under-represented in the higher education (HE) student population and over-represented in those who drop out of university without finishing their degree.

This paper reports on the research done as part of the project and identifies the hurdles and drivers affecting autistic students' experience in higher education. Differences in the support available in the project partner countries are considered. We conclude with some recommendations for how universities can support autistic students well.

2 AUTISM IN HIGHER EDUCATION

In order to deepen our understanding of the hurdles and drivers affecting autistic students in higher education across Europe, we conducted a literature review and a large-scale multinational survey involving autistic students and those supporting them. The following sections outline this approach, before presenting the findings.

2.1 Literature review methodology

In 2014, a literature review was conducted, focusing on three separate aspects of the experience of autistic students in higher education:

1. What are the characteristics and requirements of autistic students that render them different from the general higher education student population?
2. What pedagogical principles and initiatives have been used to address these differences and support needs?
3. What technological interventions have been used to support the social and academic development and independence of such students?

As the three themes show, the scope for this review was wide. It quickly became apparent from consulting previous systematic reviews in this topic area (e.g. [3][4]) that excluding studies which are not empirically rigorous would distort the bigger picture and deny the authors the possibility of critically engaging with a large number of studies on a deeper level. It would also have prevented identifying common methodological flaws in this area.

Therefore the review included all sources that would provide a fair narrative overview of the field, choosing representative examples and answering the research questions. Priority was given to sources that were most relevant to the participant age and intellectual ability range for this project. Information from non-peer-reviewed sources, such as project reports and guides for academic staff, which would not necessarily meet formal quality criteria, was also included.

227 sources were included in this review and 126 were rejected. The most common reasons for exclusion at this point were that the source did not meet the criteria on deeper reading, or that other papers were a better example of the same type of study (e.g. more participants, better methodology, better documented, more useful results).

2.2 Mapping survey methodology

Also in 2014, we conducted a mapping survey across the five Autism&Uni partner countries: United Kingdom, Finland, Poland, Netherlands and Spain. The online survey sought detailed information from seven key stakeholder groups:

1. Young autistic people not yet at university
2. Autistic students currently at university
3. Autistic students who have completed or dropped out of a university course
4. Parents and carers
5. School teachers and mentors
6. Academic or support staff working at universities
7. Autism organisations and professionals

Participants were recruited through higher education networks, disability support services, secondary education networks and autism specific groups and mailing lists. Alongside the survey, we also talked face-to-face to a number of students about their individual experiences – what affected them and how they overcame any adversity.

Over a six month period in 2014 we received 280 survey responses and 16 individual experience case studies. It should be noted that more than 50% of the responses were from young autistic adults, lending the results a strong authentic voice from the European autism community.

3 RESULTS

In the following sections we explore the typical challenges in detail, what the literature says about the context of these challenges, and the responses we received through our mapping survey.

3.1 Student numbers

Disabled students are generally underrepresented in higher education. For example in the UK and the Netherlands, about 0.35% of undergraduate students declare an autism spectrum condition. In other countries, the data may not be collected or the numbers may be even lower [5][6].

In the UK, autistic students are 25% less likely to complete their studies than non-disabled students, and 40% less likely than students with other disabilities [7]. The number of students diagnosed with an autism spectrum condition is growing [8] yet reliable statistics are not available due to the likelihood of many autistic students not actually having a diagnosis until after leaving university, and also partly due to a reluctance to disclose their condition (see following section).

3.2 The reasons for studying

Not surprisingly, many students in our survey were driven by the general advantages of studying - gaining qualifications, taking part in university life, having freedom and independence and being recognized as an “expert” in their subject. Some students’ reasons were surprising, however: Some UK students could not think of anything else to do with their lives, and some wanted to escape their home environment. The same could be seen in Finland where a minority of respondents used studying as a way to buy time when struck with indecision, or to avoid being classified as unemployed.

Many students talked about university as a “safe” place where they are not pressured to get a job, bullying is not tolerated (if their autism is disclosed) and they can be themselves, without judgement or criticism. Most of our study participants did extremely well in their studies if they completed them – they were among the best students. However of the 54 former students who did take part,

3.3 Discipline of Study

The popular perception of autistic students is that they predominantly choose STEM (science, engineering, technology and medicine) subjects. However, while autistic undergraduates are overrepresented relative to other groups in computing and the sciences, and underrepresented in education and health-related subjects, the largest group of autistic students in the UK actually study humanities and the arts [9]. In Poland, while science students were found to have high levels of autistic traits [10], humanities students also scored higher for these traits than social sciences or medical students. Our survey data confirmed this general trend, with STEM subjects being the most popular study choice at 39% of responses and arts and humanities second with 33%. There have been several initiatives aimed at supporting autistic students in STEM disciplines, such as [11], and these are well conceived. At the same time, the interest of autistic students in other subjects such as literature or history, despite their potentially problematic reliance on analysis rather than just ‘facts’, cannot be ignored and those students’ aspirations must also be respected and supported.

Overall, it has to be pointed out that the key factors predicting postsecondary success for autistic students are family characteristics, student characteristics and effective transition planning [12] - not discipline of study.

3.4 Disclosure and Accessing Support

A considerable number of university students with an autistic spectrum diagnosis are reluctant to disclose their condition, unless there are clear benefits for them in doing so [13]. Some autistic students reject the ‘label’ of diagnosis and do not disclose to anyone at the institution [14]. Some do not consider autism a deficit, and in the US a third of autistic students do not identify as ‘disabled’ [15]. This is a problem as a diagnosis, combined with the formal disclosure of the condition, is the requirement in most countries’ HE systems to receiving autism-specific support. The traditional support method generally involves ‘reasonable adjustments’ such as more time during exams, study mentors, transcripts of lectures etc. This can alleviate concerns and reduce anxiety. However, it can also separate students from their peers, increase social anxiety and a sense of being different [16].

Our survey confirmed that 47% responding students or ex-students with an autism spectrum condition had not been diagnosed by the time they started university. And nearly 30% of those who did have a diagnosis did not receive any support, either because no support was available or because they had not told the university about their condition. For those who did get support, 35% had it in place by the first week of studying. However, 48% had to wait for more than a semester.

“It took me too long to build up the courage to go to their disability support team, but by then it was too late, I had had enough and couldn’t continue at University as I could not function properly and was not happy.” (former student, UK)

3.5 Stress and Anxiety

According to Brady et al [17], young autistic adults (aged 16-21) of “high average intellectual ability” have the same cognitive intelligence as typically developing peers and yet lower emotional intelligence, putting them at greater risk of mental health difficulties. Students on the autism spectrum experience high levels of stress and anxiety at university. Autistic adults are almost three times as anxious as non-autistic adults; particularly in response to change [18], anticipation, sensory issues and positive and negative events. These events can be heightened and more regular in the intense

university environment, where students are required as part of study and student life to interact successfully socially [19] and achieve academically. Our survey data confirms this with 44% of respondents saying they have suffered from depression, and 42% have experienced anxiety at university. Students in the Autism&Uni surveys said they found these things particularly stressful:

- Group work
- Sudden changes to timetables/assignments
- Exams
- Not getting the support they needed
- Noisy classrooms and lecture theatres
- Not liking where they live
- Sensory issues
- Getting lower marks than expected
- Travelling to and from university
- Fitting in
- Presenting and talking in public

During periods of high anxiety, an autistic student may display no outward signs of distress, appearing either neutral or unresponsive until the student reaches the point of acute psychiatric crisis [20]. This can make it difficult for others, including those who know the affected person, to recognise the signs of impending crisis. At this point, continuing with the course of study can be difficult or impossible.

“I might not have dropped out if the amount of group work could have been reduced, or if I could have known my fellow students better, because then group work would not have caused so much anxiety.” (former student, Finland)

Our study also revealed that many autistic students found effective strategies for reducing stress and anxiety, e.g. sport and exercise, music and art, meditation and mindfulness, eating one’s favourite food, and talking with family and friends as well as with lecturers. Having a space to retreat to when feeling overloaded is equally effective. Several students said quiet places were really important to them e.g. in the library or going out for a walk and into green spaces. Others found going to the gym or the swimming pool helpful. Overall, it underlines the importance of such spaces to be available for when students who struggle with the sensory environment need them.

3.6 Beyond the stereotypes

Survey participants expressed concern that they did not fit the typical profile of what people expected from an autistic student – for example if they were female, if they were articulate, if they didn’t seem always to be struggling, or if they identified as lesbian, gay, bisexual or transgender (LGBT). This issue is reflected in the way students not meeting this stereotype are sometimes treated by university staff and fellow students, and how autism is portrayed in support literature.

“I still feel quite ashamed talking about my limitations to most people as I don’t instantly fit the stereotypical view of an autistic woman. I only disclose to close friends, or management at work.” (former student, UK)

The literature describing autistic students often presumes that autism and perhaps associated learning difficulties and disabilities and mental health conditions are the only or predominant factors affecting their success at university. However, autistic students can experience multiple other conditions and pressures that compound their difficulties e.g. cultural expectations, myths and language barriers [21]; race and ethnicity [22]; gender issues [23]; lower economic status [24]; and problems caused by other health issues not directly related to their autism, including physical disabilities and chronic illness [25].

“People sometimes don’t believe [I am autistic] including my old GP and friends! This upsets me as I hate people denying the reality I live in, especially as I have to work so hard to exist in their neuro-typical world. I worry it happens every time I try to explain things to new people so I’m uncomfortable talking to people about it.” (former student, UK)

This makes it difficult for universities to identify the needs of students who do not fit into a single ‘box’. As a result, these students may not be able to access all the support they are entitled to, and indeed would most likely benefit from. This affects not just students on the autism spectrum, but those with other disabilities and impairments too. For these students, an approach that does not rely on an official diagnosis and instead offered individual adjustment options as a matter of course for the entire student body could well be more effective, and certainly more inclusive and socially just.

3.7 Social skills

While many autistic students have social communication difficulties and often experience bullying [26], it is important to recognize that this does not automatically preclude them from making friends – although these friendships may be fewer in number and shorter in length than those of students not on the spectrum [27]. According to Carrington et al [28], autistic students generally express satisfaction with their friendships where mutual interests are shared, and if special interests are given a real place in interactions with autistic students they can lead to greater social adaptation abilities. Our survey data painted a slightly more negative picture, however, with around 50% of students (current and former) stating “I don’t fit in” and “I don’t have many friends” as their top reasons for not liking university.

In a UK university transition context, autistic students could be encouraged to join student clubs and societies where available to find social contacts based on their interests. However, the typically busy and noisy environment of university society fairs and other ‘freshers week’ events in the UK is particularly ill-suited to autistic students [16], and they may have to find alternative ways to get initially involved with these groups, such as via the website or social media.

3.8 Strengths and weaknesses

In a previous study [29], academic staff were asked to reflect on the strengths of the autistic student. Positive traits were highlighted such as expertise and passion for the subject, a desire and commitment to be accurate, a drive to seek knowledge and adherence to the rules. All these are traits that relate directly to academic skills and study. By contrast, the perception of weaknesses was mostly connected to concerns around social behavior and anxiety. In our study, we asked secondary school teachers and parents of autistic pupils what these would find most difficult at university. The responses very much confirmed study [29] in that meeting new people, having social interactions and integrating with their peers were by far the most prominent concerns. Other perceived weaknesses were time management and working independently.

It has been argued that in secondary education, too much emphasis is put on non-academic skills for autistic young people, confirming their deficits rather than focusing on the academic abilities and high potential [30]. More focus on strengths would arguably enable students to develop in a way that makes them more likely to apply for and graduate from higher education [30]. This could be of particular concern for those autistic learners with higher education potential who attend special rather than mainstream schools. In special education, reduced importance is placed on academic achievement and preparation to attend university [31].

3.9 Autism Awareness

Autistic learners interact with a wide range of people during their time in higher education. Some may have specific training in autistic spectrum disorders, such as specialist support workers. Others, like disability advisors and librarians, may have some understanding based on having worked with autistic people, even though they are not experts in the condition. However, tutors, peers and other individuals are reliant on their own knowledge and media portrayals of autism [32], which are often inaccurate and can lead to harmful stereotypes [33].

“I don’t tell my fellow students, because I don’t want preconceptions affecting how they see me. I’d rather be a ‘mysterious guy’ than autistic.” (student, Netherlands)

Male university students tend to have a more positive attitude towards autistic students than female ones [34]. Students are more likely to think and behave more positively towards autistic people if they are made aware of someone’s diagnosis. University staff need more information about autism than just the diagnosis in order to interact successfully with autistic students, who they will misunderstand and perceive to be rude if they fail to understand the difficulties these students face [35].

“I feel reluctant to share my problems because in the past my ‘fitness to study’ has been questioned. I’ve been asked whether university is the right environment for me.” (student, UK)

Encouragingly, in our survey, 38% of current students had told their tutors about their autism, and 40% had told their friends. The main reasons for not telling others were their perceived ignorance about what autism is, embarrassment, and not wanting to take up someone else’s time with personal issues. Given the positive effects of telling others and the advantages of tutors and peers having a good awareness of autism strengths and weaknesses, it is important for higher education institutions to raise this awareness.

3.10 Self-Advocacy

The development of self-determination and self-advocacy skills is recommended for all students with disabilities, in order for their needs to be fully met and their university study to be successful [36]. Autistic students with higher levels of self-determination and better self-advocacy skills tend to be more likely to complete their studies and have positive higher educational experience [37]. Developing these self-advocacy skills may prove particularly difficult for autistic students though, as students with less visible conditions have more difficulties adapting to university due to experiencing doubts and demands to justify their requirements from staff and peers alike, in addition to the social and communication difficulties common to autism [36].

85% of study respondents stated they did not feel comfortable explaining their needs to other people at university, and ensuring that these needs were met. They felt they would be misunderstood and dismissed, and considered being deliberately awkward since they coped quite well most of the time.

“Not everyone believes in mild autism and understands the existence of uneven skill profiles - the fact that one may seem intelligent and knowledgeable in one subject/scenario and be very bad at another” (former student, Finland)

However, when given an opportunity (like in our surveys) to talk about themselves in a safe environment, most autistic students are articulate and interesting about their problems and successes, and they clearly welcome the opportunity to share their experiences. Having to fight for appropriate support is difficult and tiring, and the effort required is not well understood. This is the issue that nearly every student wanted to talk about, more than general social or sensory problems. According to Getzel and Thoma [38], the areas of self-advocacy important to disabled students are seeking help from disability and student services; developing relationships with academic staff; constructing their own support systems at university, including peer and professional relationships; and developing self-awareness about their disability, how it affects their study and their strengths and weaknesses.

In relation to the final point, autistic students may feel marginalised and experience negative emotions as support they receive tends to focus on their deficits and ‘special needs’ rather than their academic ability, even if they are particularly gifted students [39]. On the other hand, families of students with autism often express a desire for the student to be ‘normal’ and fit in [40]. These conflicting perspectives can make it hard for autistic students to adopt a positive identity relating to their autism and this can affect their ability to advocate for themselves effectively.

3.11 The 'broken' student

In supporting guidance aimed at disabled students and their families, the onus is put mainly on the student to adapt, change and develop all these skills independently [41], despite the difficulty for autistic students in adapting to change where support may be limited and anxiety levels are likely to be high already [42]. This adds weight to the perception that in higher education the disabled student is the problem and not the institution, which is an unhelpful and negative view of disability.

However, it is this view that forms the basis of support offered by the likes of the Disabled Students Allowance in, for example, the UK and Germany. This approach aims to adapt the student to university and not the other way around [43][44]. ‘Othering’ of the autistic student in this way does not promote inclusion in the university environment or encourage the institution and its people to change their practices. It is a retroactive approach that alters existing material to fit the needs of specific individuals. A more proactive strategy is called for, which considers the needs and preferences of diverse student groups from the outset, when the learning experience is designed. This is the ethos of Universal Design for Learning, a concept we will elaborate on in our discussion.

3.12 Unrealistic expectations

Our study showed that students who had been given unrealistic expectations of their peers, such as that they would in the main be hardworking and interested in debate rather than socializing, became upset when they found this was not true. A mismatch of expectations and reality seems to be a real problem – however much research students do about a course or a university in advance, they seem to be disappointed or even outraged that university is not like they hoped it would be and as a consequence they did not feel well prepared.

In many ways university is very different to school – less structure, having to manage their own time, not being told exactly what to do to get a good mark or how many hours they should study outside

class, having to choose their own modules and not always getting their own way, having to live independently if they leave home. In other ways it is the same – most of their peers are not obsessed with their course and have other priorities. Even though they have now specialized in their favorite subject, they still have to study topics they already know or do not like, and they are no more likely to fit in socially. Some thought university would be a “magic bullet” where everything would be different and they could have a new start, leaving the label of autism behind. The realization that this may not be the case then caused new anxieties.

4 SUMMARY

Transition to higher education can be very difficult for autistic students. Some of the challenges have to do with the higher education system and the organization of disabled student support, others relate to the characteristics of autism and how they affect academic and social life at university. There are specific issues autistic students may be experiencing for the first time in post-compulsory education, such as group work, adjusting to independent living and study, and the ‘battle’ to get appropriate support [45]. There may also be a mismatch between the expectations of what university study will be like, and the reality. Our research findings point towards two key phases of the transition from school to university, during which a multitude of challenges occur:

1. When the student prepares for university

Typical considerations are whether to go to university at all, which university, which course to study, whether to move away from home, how to integrate socially, not knowing how to ask for support or what support is available, etc. These planning activities can be daunting and particularly so for students with autism due to possible deficits in social imagination and a tendency to be inflexible in their thinking. Young adults may decide not to go to university, even if helpful support is available.

2. The arrival and initial settling in phase

Being in an unfamiliar physical environment with student peers who are also not familiar with the environment and what is expected of them academically and socially. Expectations are high and often do not match reality, e.g. regarding the course content, their own grades and the studiousness of their peers. Getting used to study situations and working much more independently than in secondary education can be unnerving. Most neuro-typical students can adapt reasonably quickly and draw from the support of their new-found friends, but for autistic students small challenges can rapidly lead to anxiety and further isolation, depression, disengagement and eventually drop-out from the course.

Autistic young people not entering higher education at all, or dropping out early, is clearly an immense loss to European society and economies as many have particular strengths to offer, e.g. strong dedication and focus on their chosen study subject, attention to detail, adherence to rules, a high work ethic and a propensity to thinking rationally and logically [46][29].

*“What could have prevented me dropping out? Diagnosis. Self-insight. Appropriate support.”
(former student, Netherlands)*

The survey responses from all countries reflected a variety of concerns, often not just focusing on study skills but on broader issues: failure to communicate with university bureaucracy, disorientation in new environments, difficulty dealing with certain sensory stimuli, lack of connection with fellow students, not knowing who or where to ask for help or trouble adjusting to independent adult life.

“I’m afraid that my son will not be able to navigate the maze of buildings, will get really upset because he cannot find his way somewhere, and then behave in a socially unacceptable manner.” (parent, Poland)

Several respondents recounted positive experiences and provided valuable insights into how they managed to succeed in certain situations or with their degree studies as a whole. Other positive examples constituted good practice on behalf of academic or support staff, and these also helped contextualizing the challenges student face.

“I have always wanted to do research, especially with languages, and studying makes it possible.” (student, Finland)

“We were all assigned a personal tutor. Mine was very proactive in getting to know me as a person and organising regular meetings with me.” (former student, UK)

“In high school I was ridiculed by my peers. This does not happen at university, where my fellow students treat me with respect.” (student, Spain)

4.1 Summary of key challenges

Table 2: Summary of challenges faced by autistic students

1. The social and physical environment at university	<ul style="list-style-type: none"> • difficulty picking up unwritten social rules when interacting with tutors and fellow students • difficulty tolerating background noise, lighting, crowding or other sensory aspects of the university environment • handling the social isolation that often comes with living in a new environment
2. Lack of appropriate support	<ul style="list-style-type: none"> • lack of access to appropriate support right from the start, eg. due to lack of diagnosis • a focus on the 'deficits' of autism, rather than students' strengths • lack of consistency in reasonable adjustments, autism-specific services and personal support
3. Unrealistic expectations	<ul style="list-style-type: none"> • what university study is really like • content of study subject or course • performing at the same high standard as in secondary education • fellow students' interests and dedication
4. Challenges with assessments (even when mastering the subject area)	<ul style="list-style-type: none"> • difficulty interpreting ambiguous or open assignment briefs correctly • lack of understanding why something needs to be done • difficulty planning studies and revision • uncertainty how much time to spend on a given task
5. Transition requiring more effort than for the average student	<ul style="list-style-type: none"> • moving away from home for the first time • time management and establishing routines • an unfamiliarity with advocating effectively for oneself

5 FUTURE DIRECTIONS

As we have shown above, there can be a multitude of potential challenges to the HE success of autistic students. In trying to address and alleviate these it is tempting to stereotype the condition and target the autistic student body with a one-size-fits all support programme. One must not forget, however, that autistic people are a very heterogeneous group and what is a challenge for some may not present particular difficulties to others. In this sense, they are no different from any group of disabled or otherwise diverse students. One-size-fits-all solutions seldom work, and where they do it is arguable whether more flexibility and greater inclusiveness would create better results anyway (e.g. regarding student performance, retention or general satisfaction with the course and institution).

Madriaga and Goodley [47] have proposed a more socially-just approach that understands the desires as well as problems of disabled students. It would not require students to disclose their differences or seek extra support, but support all students by default. This is particularly relevant to autism, where so many students do not disclose or not seek support. Their idea is very much in line with the concept of Universal Design, which originated in the field of architecture in the 1970s to emphasize design that allows for a wide range of users, including those with disabilities [48].

Universal Design for Learning (UDL) refers to engaging and supporting diverse groups of students, regardless of their background, status or disability [49]. A common misconception is that Universal Design promotes a 'one-size-fits-all' approach – but that is not the case. What it really means is the availability of options: providing students with multiple and varied opportunities to participate in learning, and to demonstrate their understanding. A UDL approach favors educational strategies that are proactively designed to support multiple paths through learning, rather than focusing on retroactively altering existing material to fit the needs of a specific group [49].

An example of *proactive* design is giving ALL students options for how they can present assignment work, in line with their communication abilities and preferences. An example of *retroactive* design is the practice of making 'reasonable adjustments' to existing learning materials and examination

arrangements. Another example of proactive design is to record all lectures and making them available to all students as a matter of course, rather than allowing a select few to capture recordings for their own use. Adopting UDL is a positive step because if adjustments are made on an individual basis only - as opposed to being available to anyone who requests them, or even implemented as a matter of course for the entire student body - students who have no diagnosis or who have not declared a disability will be at a disadvantage at university. Further, the practice of singling out disabled students by agreeing individual reasonable adjustment plans does not promote full inclusion in the university environment, or encourage the institution and its staff to change their practices [50].

Socially just pedagogies move away from traditional teaching methods and the teacher-student division, and value diversity rather than emphasizing 'normalcy' and 'deficits' - deviations from the mainstream [51]. Approaches like Universal Design place the student at the center of the design of teaching, curriculum, university procedures and the built environment. By providing all students with options that take account of their potential strengths and weaknesses, the hurdles for autistic students will be reduced, as will those for other groups that do not match the ideal of a 'typical' student.

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