WIDENING ACCESS TO HIGHER EDUCATION FOR STUDENTS ON THE AUTISM SPECTRUM – THE EUROPEAN AUTISM&UNI PROJECT

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Abstract

Autism&Uni is a European-funded initiative with partners in five countries (UK, Finland, Poland, Netherlands and Spain). Our aim is to support greater numbers of young adults on the autism spectrum to gain access to Higher Education (HE) and to navigate the transition from School successfully. This paper summarises the project rationale, the research undertaken and its methodology, and finally the project outcomes. The project adopted a two-pronged approach to widening access for autistics students in higher education by a) initiating change in the higher education sector through sharing best practice, and b) equipping young autistic people with the information and strategies they require to overcome the challenges they face, in the form of an online toolkit that can be freely adopted and adapted by any European university. We have involved autistic students at every stage of the project, surveying their needs and aspirations, and seeking feedback on content and design solutions. Their expressed needs and preferences have shaped the project’s end products.

Keywords: higher education, autism, disability support, inclusion, research

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. Autism is a spectrum condition, which means that it affects different people in different ways. A substantial proportion of autistic people is of average or advanced intellectual abilities and academically competent, although some have an additional learning disability. 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.

On the other hand, 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 recognized by businesses world-wide.

Young people on the autism spectrum, like any other young people, want to grow up and lead full and independent lives. But although autism is not an indicator of academic ability, many find it difficult to enter university and those who do start a degree course are prone to dropping out early.

Autistic students who receive appropriate support in a timely manner thrive in higher education. Their skills and expertise are recognized and they have access to world class lectures and library facilities to support their special interests, and other opportunities that enable them to grow and develop.
Autism&Uni (www.autism-uni.org) aims to help these students navigate the transition from school to university successfully, so that they can fulfill their full potential. The project ran from October 2013 to March 2016 and involved 6 partners:

**Leeds Beckett University, UK**
Leeds Beckett University (former Leeds Metropolitan University) has a long history of autism research in the HE, learning and child development context. The university leads the Autism&Uni project.

**The Foundation of European Initiatives, UK**
The Foundation for European Initiatives is a non-profit organisation that assists people with conditions such as cerebral palsy, autism and learning disabilities.

**Kekuspuisto Vocational College, Finland**
Keskuspuisto Vocational College offers special education to students with disabilities and functions as a national centre for developing special education practice, in particular for students with autism spectrum disorders.

**Autismo Burgos, Spain**
Autismo Burgos is a non-profit organisation that promotes the well-being of people with autism spectrum disorders and their families.

**Technical University Eindhoven, Netherlands**
Eindhoven University of Technology is a research university located in a high-tech industry area of The Netherlands, attracting an above average number of autistic people.

**The Academy of Humanities and Economics in Lodz, Poland**
The Academy of Humanities and Economics focuses on research and development of e-learning platforms and innovative teaching curricula.

### 2 KEY CHALLENGES FACED BY AUTISTIC STUDENTS

To find out about the needs and aspirations of autistic students, and to define current good practice, we conducted a multi-national questionnaire survey in the project partner countries. We also talked to autistic students about their experiences, reviewed research and professional literature, and mapped educational provision and legislation concerning autistic children and youth across Europe. Our research has shown that there are many challenges for autistic students:

**The social and physical environment**
- 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

**Lack of appropriate support**
- lack of access to appropriate support right from the start
- a focus on the ‘deficits’ of autism, rather than the strengths students can bring
- lack of consistency in reasonable adjustments, autism-specific services and personal support

**Unrealistic expectations**
- 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

**Challenges concerning assessment (even when mastering the subject matter)**
- difficulty interpreting ambiguous and 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
Transitioning to adult life requiring more effort than it would for the average student

- moving away from home for the first time
- time management and establishing routines
- an unfamiliarity with advocating effectively for oneself

Arguably many of these are challenges for any new student. But while most can adapt reasonably quickly and draw from the support of their friends, for autistic students these challenges can rapidly lead to anxiety, further isolation, depression and eventually they may drop out from their course of study completely.

This is clearly an immense loss to European society and economies as many autistic students 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.

It should be acknowledged here that some European HE institutions already provide combinations of services for autistic students and adjustments, e.g.:

- assessment and support plans by university disability teams
- extra time and a separate room in exams
- permission to use laptop computers to type written exams
- clarification of ambiguous wording by an assistant in exams and study assignments
- reduced tuition fees
- special arrangements in student accommodation
- assistive software on all university computers, or for individual use
- personal mentoring or coaching
- extra involvement by study advisors, including extra time allocated to planning, and conveying information about the student’s needs to academic staff
- individual or group sessions with study advisors specialising in autism
- alternatives to or special arrangements for group work and oral presentations
- maps, written directions and other support to help with finding study locations
- all lecture slides provided in advance
- permission to record lectures
- designated seats, computers etc. in lecture halls and classrooms

However, knowledge of how best to support autistic students is not consistent across Europe and often varies within a country. Pockets of best practice exist, and Autism&Uni aims to highlight and promote these in order to improve the prospects and number of HE students on the autism spectrum.

3 DIFFERENCES ACROSS THE PARTNER COUNTRIES

The level and availability of services and adjustments for autistic students varies widely between the countries that have taken part in the Autism&Uni project. Each system creates different obstacles and opportunities for autistic student and good professional practice needs to recognise these.

In the UK, students are assessed and receive service plans from disability teams within HE institutions. A wide range of services and resources are considered reasonable adjustments. A common service model is individualised, personal support by a mentor, who can be either a professional or a student trained in the task. Autistic students can receive a financial benefit called Disabled Students’ Allowance.

In the Netherlands and Finland, HE institutions typically offer autistic students counselling by a psychologist, study advisor with training in autism issues, or similar professional. Group sessions may be offered to support planning studies, managing anxiety, developing study skills, or other specific areas. Other types of support, such as financial benefits or long-term support, often crucial to the student’s successful progress, may be provided by health care or disability services outside the HE system. Complex rules and legislation can pose challenges to both students and their supporters.

The situation in Poland bears resemblance to these countries, but there are at this point very few autistic students declaring their diagnosis to HE institutions, and the development of specific provision
is in early stages. In Spain, the development of provision has been driven by autism organisations and innovative projects run by universities, especially in the area of supporting secondary education students and creating accessible entrance examination conditions. At the national level, the range of services and adjustments is broad, but there is variation depending on provincial administration.

4 ADRESSING THE PROBLEM

The Autism&Uni project adopted a two-pronged approach to widening access for autistics students in higher education (see also Fig. 1):

1) Initiating change in the higher education sector by sharing best practice across Europe through a Best Practice Guide targeted at Higher Education Managers, Lecturers and Tutors, and Disability Support staff within and outside of Higher Education Institutions. Visit www.autism-uni.org/bestpractice to download the guides.

2) Equipping young autistic people with the information and strategies they require to overcome the challenges they face, through an Online Toolkit that can be freely adopted and adapted by any university. Visit www.autism-uni.org/toolkits for full details.

Figure 1: Addressing both the environment and the individual student

4.1 Best Practice Guides

We have developed three guides with the help of autistic students, their parents, university tutors, school teachers, and autism support staff. These guides summarize our findings and highlight best practice, particularly in the project partner countries United Kingdom, Finland, The Netherlands, Poland and Spain. Each guide is aimed at a specific group of people who are involved in supporting autistic students at university, outside the family:

GUIDE 1: For HEI managers and senior academics
This section is for managers and senior academics at universities and higher education institutions, providing you with information and evidence to help you develop policies and practices that will benefit autistic students and improve the student experience at your institution.

GUIDE 2: For HE lecturers and tutors
This section is for teaching staff at HEIs. We share with you practical tips based on evidence from our research to enable you to make your learning and teaching practices more accessible and support you to build better relationships with autistic students.
GUIDE 3: For professionals supporting autistic students within or outside HE Institutions
This section is for specialists directly supporting autistic students. This may be as part of a disability support team within a HEI, or for an independent organization that provides services to HE. We share insights from our research and from good practice across Europe that will help you improve student experiences and engagement with your information and services, and to develop your expertise.

Our research has shown that even small adjustments and changes in professional practice can make a noticeable difference to autistic students' university experience and study success. Each guide therefore focuses on ‘Takeaways’ – insights, ideas and prompts for making a positive change and good practice to share with colleagues, as well as ‘Calls to Action’ – direct action one can take immediately and without the help of others. An example of takeaways and calls to action for HE Lecturers is shown below.

Selected Takeaways for HE Lecturers (good practice to adopt and share)
1) When talking to a student, focus not just on challenges, but identify the student’s strengths and what they can contribute to study situations; many autistic students have a strong dedication and focus on their chosen study subject, attention to detail and a high work ethic.
2) Encourage strong relationships between personal tutors and students; autistic students benefit from consistency in these relationships, with the same contact person throughout their study.
3) When you are uncertain about how to provide support or adjust provision, arrange meetings with the student and their support worker, study advisor, counsellor or disability advisor.
4) Communicate with student services, disability workers or other relevant professionals if you are concerned about signs of depression, anxiety or declining study performance.
5) When arranging meetings, try to ensure that the room is free of visual and auditory distractions that may prevent the student from focusing; do not hesitate to ask the student what their specific needs are in this respect.
6) Be aware of ways to create accessible physical and learning environments that are important for autistic students and can benefit others as well. This includes avoiding ambiguous information, providing lecture material in advance, supporting group work, etc.

Selected Calls to Action for HE Lecturers and Tutors (what they can do right now)
1) Learn about the autism spectrum in general and about your student’s specific challenges and requirements; Request and undergo training in supporting autistic students.
2) Get in touch with disability or autism support staff at your institution and discuss what changes you could make to your teaching practice; sometimes these changes are individual to you and not easily transferable, so it is worth exploring them in depth.
3) If you have the opportunity, talk to an autistic student in the later stage of their studies and explore what support was useful and what additional support would have helped.
4) Check assignment briefs and exam questions for possible ambiguities; be clear about when ambiguity has a pedagogical purpose and where it is introduced accidentally.
5) Make it clear that during teaching sessions any student can leave the room if they feel anxious or overwhelmed, and that they will not be criticised or penalised for doing so.
6) Show a positive attitude towards arrangements and devices that allow the student to manage reactions to the sensory environment, e.g. designated seats, wearing hats, hoods or glasses.

For the full guides, which are completely free and available in 5 languages, please visit the Autism&Uni project website at [www.autism-uni.org/bestpractice](http://www.autism-uni.org/bestpractice).

4.2 Online Toolkit
We have created an online toolkit that gives students information and strategies for overcoming the challenges they typically encounter at university. The underlying ethos of the toolkit is that students can use it in their own time, do research about issues concerning them, and come back to it when particular difficulties arise. Some of the toolkit themes are shown in Table 1. Under each theme, the student can explore background information, find out why the information may be relevant to them (or not), act on a call to action and consider some practical tips and activities that may help in overcoming the challenge faced. In response to feedback from students who were involved in the design and evaluation of the toolkit, the content is text-centred, adopting a factual and non-judgemental tone and is presented in a logical and easy-to-navigate interface.
<table>
<thead>
<tr>
<th>Topic title</th>
<th>Rationale / Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why declare a disability</td>
<td>Many autistic students do not declare their autism before starting university, which prevents access to support at the start of the study when it matters most.</td>
</tr>
<tr>
<td>What is the Study Needs Assessment?</td>
<td>To reduce anxiety about being interviewed and discussing uncomfortable issues. (Study Needs Assessment is a UK term, similar processes exist in other countries)</td>
</tr>
<tr>
<td>Managing expectations</td>
<td>Many autistic students (and their parents) have expectations that do not match the real situation at university. The surveys provided many accounts and quotes to support this.</td>
</tr>
<tr>
<td>Help with getting to campus locations</td>
<td>Students reported getting repeatedly lost on campus and not remembering items on their timetable. And when they are late there is a reluctance to enter the room.</td>
</tr>
<tr>
<td>Typical study situations</td>
<td>Advice on what to do in certain unfamiliar situations, e.g. during a lecture, when working with other students in a team, in a tutorial, etc.</td>
</tr>
<tr>
<td>Managing difficult situations</td>
<td>It is important for students to advocate for themselves. Parents and teachers were very vocal about this, and a number of typical situations were identified (e.g. talking about one's autism, complaining about something, when and how to arrange a meeting with a tutor)</td>
</tr>
</tbody>
</table>

The toolkit is freely available for universities to adopt and adapt. Adaptation is necessary as some of the information is specific to each institution, e.g. the support services available at that institution and details of the buildings, people and infrastructure.
The toolkit was developed using a participatory design approach, involving autistic students in the design of both content and visual appearance. Figure 3 shows participants in the second of three design workshops.

![Figure 3: Participatory Design Workshop](image)

For more information on the online toolkit and how it can be adapted to different institutions and languages, please visit [www.autism-uni.org/toolkits](http://www.autism-uni.org/toolkits).

5 ACKNOWLEDGEMENTS AND DISCLAIMER

The research leading up to this paper has been made possible thanks to the AUTHEW (Autism&Uni) project, part of the Erasmus Lifelong Learning Programme. The Autism&Uni project has been funded with support from the European Commission. This publication reflects the views only of the authors, and the Commission cannot be held responsible for any use, which may be made of the information contained therein.

![Lifelong Learning Programme](image)