autism&uni

A guide to best practice in supporting higher education students on the autism spectrum

Best Practice for HE lecturers and tutors

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Guide 2





Source: NHS, Brugha et al (2012)

Introduction

About Autism

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 problemsolving, 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.

A note on language

We have chosen to use the terms "autistic students" and "students on the autism spectrum". This is based on recent research (Kenny et al., 2015) showing that most autistic adults prefer this 'identity first' language to the 'person first' terminology often used by autism professionals (for example, "students with autism"). The autistic people involved in the Autism&Uni project also prefer these terms.



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About Autism&Uni

Autism&Uni is an EU-funded project with partners in five countries. 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 successfully.

To find out about the needs and aspirations of autistic students, and to define current good practice, we conducted a questionnaire survey, talked to 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 who want to enter and succeed in HE.



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Challenges faced by 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 by the student

- · 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

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

Project website: www.autism-uni.org

Challenges faced by autistic students

Arguably many of these are challenges for any new student. Most can adapt reasonably quickly and draw from the support of their friends. But 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.

Adopt our free online toolkit

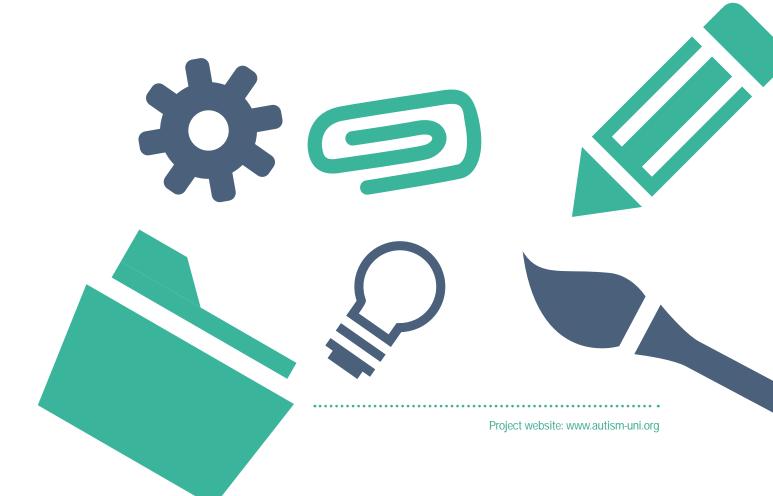
The Autism&Uni project supports students during this critical transition period through an online toolkit. The toolkit is available in several languages and can be adapted to a university's specific needs, environment and support structure.

Visit www.autism-uni.org/toolkits to find out more.



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"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)

Project website: www.autism-uni.org

About this guide

We have developed this guide with the help of autistic students, their parents, university tutors, school teachers, and autism support staff. It summarises our findings and highlights best practice, particularly in the project partner countries United Kingdom, Finland, The Netherlands, Poland and Spain. All quotes are from surveys and interviews we conducted in these countries in 2014.

Some European HE institutions (HEI) already provide combinations of the following services and adjustments (these are examples only):

- 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 this guide aims to highlight and promote these in order to improve the prospects and number of HE students on the autism spectrum. <u>07</u>

How to use this guide

We recognise that one size may not fit all, so we have created three guides aimed at specific groups of people who are involved in supporting autistic students at university, outside the family.



This guide 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.

This guide 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. This guide is for specialists directly supporting autistic students. This may be as part of a disability support team within a HEI, or for an independent organisation 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.

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How to use this guide

Each guide 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 you can take immediately and without the help of others.

Some of the examples of best practice may not be directly applicable in your country or organisation. Where this happens, it may still be possible to spot an underlying principle that can be included in your professional practice.

Autistic students who receive appropriate support in a timely manner thrive in higher education. Their skills and expertise are recognised 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. Following this guide will help you to help students make the most of their time studying and living at university.

If you would like to obtain one of the other guides in this series, please visit www.autism-uni.org/bestpractice



"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)

"I'm always afraid of being turned away or not being able to explain myself well, or being misunderstood and having that change the way I'm treated."

(former student, UK)

Best Practice for HE lecturers and tutors

Background

Autistic students are all different, but many share common worries according to the Autism&Uni surveys, including:

communicating and working in groups	 concern about their level of disability being misunderstood or belittled 	
ambiguous questions in interviews, assignments and exams	fear of public speaking	
not knowing who to ask for support	tendency to go off on tangents or talk too long about their	
getting lost	special interests	
being stressed or distracted by certain sensory aspects	"The hardest things for my son are planning and organising his work, relating to other students, and asking for help even when he urgently needs it."	

Why is this a problem?

Autistic students and the individuals and organisations supporting them told us that they have had challenges persuading academic staff to make reasonable adjustments to coursework, deadlines and usual teaching practices.

Of course many students find group work challenging, and many would like to have longer deadlines or be given assignments that require no interpretation on their part and so on. However, the difference with autistic students is that they have limited capacity to deal with these challenges and their levels of anxiety are much higher.

Simply saying "everything will be OK" does not help. Expectations need to be made clear and explicit, including learning outcomes, assignment briefs and marking schemes. "Tutors are already overstressed and overworked. Add to that the fact they simply lack the specific knowledge to understand the problem, I find it very hard to explain my needs and even more so to persuade them to help me with them."

(student, UK)

"I find that I perform better on tasks where I am either given total freedom (e.g. devising my own question and answering it, on courses taught by lecturers who reward originality) or where there are very rigid instructions. I perform less well in essays where there are implicit rules to follow, but which are not spelled out."

(student, UK)

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Project website: www.autism-uni.org

What can we do about it?

The Autism&Uni survey and mapping of provision in the partner countries brought up several positive examples of local and national organisations with autism-specific expertise providing advice and training to HEI staff and departments.

These include for example Handikap&Studie in the NL, Autismisäätiö and Omavoima services in Finland, JIM in Poland, Autismo Burgos in Spain, the National Autistic Society in the UK (see also the list of case studies at the end of this guide)

Personal tutors can be key to the success of autistic students, as many of them find it difficult to initiate communication or find appropriate services without help when they are in distress. Especially when there is no consistent disability support provision within HE, the personal tutor may be the first or only person who is aware of emerging challenges affecting the student's progress, and a natural point of contact between the HEI and external organisations that provide specialist autism support. Lecturers can also have a significant role in decision-making concerning reasonable adjustments, and should have a basic knowledge of autism to be able to make informed decisions.

The University of Brighton, UK, developed a project bringing together the Disability Services Team and the Centre for Learning and Teaching (Morris, 2011). It is clear from this study that accessible learning environments which consider sensory issues and inclusive teaching practices are as important for the success of autistic students as individual support, and it is recommended that teaching staff read this article and its recommendations in full.

See also our information on Universal Design for Learning (UDL) on page 21

"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 whether there was a problem or not."

(former student, UK)

Takeaways (good practice to adopt and share)



These focus on university-wide and strategic changes that require management support.

- When talking to a student, focus not just on what may be 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.
- Encourage strong relationships between personal tutors and students; autistic students particularly benefit from consistency in these relationships, with the same contact person throughout their time at university
- If you are asked to make decisions about reasonable adjustments or special arrangements, find out if your institution has general guidelines concerning autistic students
- When you are uncertain about how to provide support or adjust provision, arrange meetings with the student and their support

worker, study advisor, student counsellor, disability advisor or other professionals who may be able to advise you

- Communicate with student services, disability workers or other relevant professionals if you are concerned about signs of depression, anxiety or declining study performance
- 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
- Speak to the autistic student about whether they are comfortable to tell other students about their autism; generally this is a good idea, but fellow students need to have sufficient knowledge about the autism condition

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- Be aware of ways to create accessible physical and learning environments that are important for autistic students (and can benefit others as well):
 - Make boundaries, expectations and learning outcomes clear and explicit, either by providing the information in the session or making it available online
 - Check that information you give to students is clear, concise and unambiguous. Always explain why you ask students to do something.
 - When marking be aware that misunderstandings can arise when autistic students try to interpret ambiguous expressions
 - If possible, provide presentation slides and handouts in advance, and consider recording lectures on audio or video; these practices are really helpful to autistic students as they can reduce anxiety and help them organise their work

- When you need to change rooms, assessment conditions or other plans, give as much advance notice as possible
- Provide support around working in groups, intervening when communication appears to fail, division of work is unfair, or any member of the group is excluded by others; encourage the group to set 'ground rules' before work starts
- Provide support around oral presentation skills and be prepared to discount autismrelated difficulties such as lack of body language, eye contact, speaking very fast or slow
- Be open to exploring new, perhaps unorthodox, ways of working; encourage students to study in their own way, with flexible approaches to deadlines, coursework and modes of study if that helps them to focus on the teaching material better.

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Calls to action (what you can do right now)

Learn about the autism spectrum in general and about your student's specific challenges and requirements

Request and undergo training in supporting autistic students and discuss training needs with other staff members who work with your students

If you have already had training, share your knowledge with colleagues

Project website: www.autism-uni.org

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

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

If suitable training is not available, make a request to a relevant department within your institution or to an external organization with autism expertise that they start creating such training. The UK National Autistic Society (www.autism.org.uk) provides useful training for university staff. Consider asking for this as part of your continuing professional development. <u>17</u>

Calls to action (what you can do right now)

Show a positive attitude towards arrangements and devices that allow the student to manage reactions to the sensory environment, such as designated seats, wearing hats, hoods or tinted lenses indoors, wearing headphones, or handling 'stress toys' *S*€

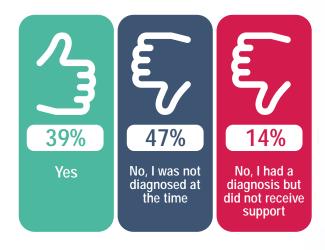
Make it clear that during teaching sessions any student can leave the room if they feel anxious or overwhelmed, and that they will not be criticised or penalised for doing so

Check assignment briefs and exam questions for possible ambiguities; this does not mean removing all ambiguity, but being clear about when ambiguity has a pedagogical purpose and where it is introduced accidentally.

The importance of well-timed support

The Autism&Uni surveys included students who had dropped out of university and those who had successfully completed their courses. Timely support, or the lack of it, was a key factor in retention of these students.

During your studies, did you receive support related to your autism?



During your studies, did you receive support related to your autism?

Before I started the course 21% In the first week of my course 14% In the first month of my course 7% Before the end of the first semester 10% Later than the first semester

48%



"Nearly all undergraduate level teaching of information technology is done in a 'sandwich' style: every two hours you switch to a [new] topic that's entirely different from the previous one. Only when I started planning my own study schedules AGAINST all recommendations, focusing on one type of subject matter per study period, did I begin to learn effectively."

(student, Finland)

"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)

Universal Design for Learning (UDL)

The concept of Universal Design originated in the field of architecture to emphasise design that allows for a wide range of users, including those with disabilities. Universal Design for Learning refers to engaging and supporting diverse groups of students, regardless of their background, status or disability.

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 favours 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.

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.

Sources: Bublitz et al (2015), CAST (2011)



Visit our project website for more information www.autism-uni.org

Case studies and useful links from Autism&Uni partner countries

We have collected case studies of innovative approaches to autism support from the countries involved in the Autism&Uni project. These are examples of best practice, e.g. where an organisation achieves something above and beyond what everyone else is doing.



Case Study

Omapolku ry / Omavoima deliver individual and group counselling and coaching services to adolescents and adults with various neurological conditions, including autistic HE students. These services support the development of independent living skills, life management, study planning, and negotiating transitions such as changing courses.

The organisation provides information about autism for university staff in charge of writing recommendations for reasonable adjustments and advocates for individual students to help them get appropriate adjustments and personalised learning plans.

Unlike many Finnish organisations, Omavoima systematically records the numbers of autistic clients receiving each type of service, collects feedback about the experienced outcomes using questionnaires designed for this specific purpose, and arranges follow-up meetings with former clients to monitor their wellbeing. This allows the organization to accumulate muchneeded evidence about the effectiveness of interventions in the Finnish system, and to move towards genuinely evidencebased practice, which could help other organisations to make decisions about trying similar service models.

Contact

Heidi Multanen, Counsellor www.omavoima.info

Useful Links

- 1. Autismi- ja Aspergerliitto ry www.autismiliitto.fi
- Esteetön opiskelu korkea-asteen oppilaitoksissa (ESOK) www.esok.fi
- Kansaneläkelaitos, Oma Väylä hanke www.kela.fi/omavayla
- Omapolku ry, Omavoima neuropsykiatriset ohjaus- ja valmennuspalvelut www.omapolku.fi/omavoima
- 5 Otus säätiö, Korkeakoulujen saavutettavuus -selvitys 2016 www.otus.fi/index.php/julkaisut/kaikkijulkaisut

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The Netherlands

Case Study

Handicap+Studie is the Dutch centre at the forefront of supporting students with disabilities. The organisation is a service and information point for educational institutions.

Its mission is to allow disabled students to successfully participate in higher education of their choice. Advisors identify what is important to students and translate their questions into support and opportunities for successful study.

Handicap+Studie's key provision is the support for alternative, flexible learning routes, following the ideas of Universal Design for Learning (UDL). Students are seen as individuals. Their differences are taken into account and they can then follow the learning path that suits them best.

Contact

Eline Thijssen, Consultant Nelleke den Boer, Advisor and Trainer www.handicap-studie.nl

Poland



Case Study

Jaś i Małgosia (JiM) provide high quality assistance to people with autism and other disabilities. The organisation conducts awareness-raising campaigns about autism. They train teachers and therapists throughout Poland and organise peer support groups for parents. There is also the JiM Therapy Centre, which cares for around a thousand young people with autism as well as other developmental disabilities. JiM's services are provided completely free of charge.

JiM is unique in the central Polish city of Łódź, where it is difficult to find reliable autism diagnosis services and professional support for students and their families – JiM is a highly-valued single point of contact for all of these services.

Contact

Marta Charbicka Director of the Children's Therapy Centre www.jim.org

Useful links

- 1. Handicap+Studie www.handicap-studie.nl
- 2. Nederlandse Vereniging voor Autisme www.autisme.nl
- 3. STUMASS Wonen voor studenten met ASS

www.stumass.nl

4. Landelijk Netwerk Autisme www.landelijknetwerkautisme.nl

Useful Links

- 1. Fundacja Jaś i Małgosia w Łodzi www.jim.org/fundacja
- 2. Fundacja Synapsis w Warszawie synapsis. org.pl
- Stowarzyszenie Dalej Razem w Zielonej Górze www.dalejrazem.pl
- Stowarzyszenie Uczymy się żyć razem w Opolu www.autyzmopole.pl
- Navicula Centrum diagnozy i terapii autyzmu w Łodzi www.navicula.pl

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Spain



Case Study

Autismo Burgos offers a programme for autistic students, providing a complete guide with specific steps to support access to university and help students in their first year to cope with every aspect of this experience. The process includes guidance counselling, adaptations to the university entry test, collaboration with the university service for students with special educational needs, information about scholarships and academic support.

The student receives a personalised programme in the early days of their course, allocation of a personal assistant, help to establish a schedule, find support within the university context, make a decision about communicating their diagnosis to their peers, campus tours and more.

Contact

María Merino Psychologist www.autismoburgos.org

United Kingdom

Case Study

The University of Sheffield employs disabled students to be 'Disability Champions' who are paid to speak about support available to current and prospective students. Disability Champions also provide transition support for new autistic students through an e-mentoring scheme and one-day transition events.

This gives autistic students a chance to address any queries or concerns they have before the start of the semester. While not all autistic students may want to spend time with other autistic students, many find it helpful to meet others who are in the same situation and also those who are further ahead in their studies and doing well, in order to gather information about coping and thriving at university.

Contact

Gayle McKay, Disability Transition Officer www.sheffield.ac.uk/disability

Useful links

- 1. Confederación Autismo España www.autismo.org.es
- 2. Federación Autismo Castilla y León www.autismocastillayleon.com
- 3. Autismo Burgos www.autismoburgos.es
- Asociación Española de Profesionales del Autismo (AETAPI) www.aetapi.org

Useful links

- 1. National Autistic Society www.autism.org.uk
- 2. ASD Wales www.asdinfowales.co.uk
- 3. Scottish Autism www.scottishautism.org
- 4. Autism Northern Ireland www.autismni.org
- 5. Autism West Midlands www.autismwestmidlands.org.uk

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UK

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Heta's work for Autism&Uni has focused on dissemination and differences in cultural contexts and service systems. She has a degree in special education, and one in biology. Heta identifies as autistic and has been involved with autism for eighteen years as a writer, translator, educator, project worker and NGO activist.

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Our Partners



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Tobajas, F., De Armas, V., Cabello, M.D., Grijalvo, F., 2014. Supporting students with special needs at university through peer mentoring, in: Global Engineering Education Conference (EDUCON), 2014 IEEE. IEEE, pp. 701–705. "I dropped out of my first university. I couldn't find out where I had to be or what I was expected to do. Socially it was very difficult and I didn't have any real friends, just a lot of people who took advantage of me. I really, really struggled and ended up having a serious breakdown.

I wasn't ready for uni then. I couldn't live independently without putting myself at risk. It was horrible, even though I'm very intelligent, the social side and organisation required was beyond me.

My second attempt at uni worked much better. I fast-tracked my degree in 2 years and one exceptional individual showed me what a real friendship was, for the very first time in my life."

(former student, UK)

For more information please visit www.autism-uni.org

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