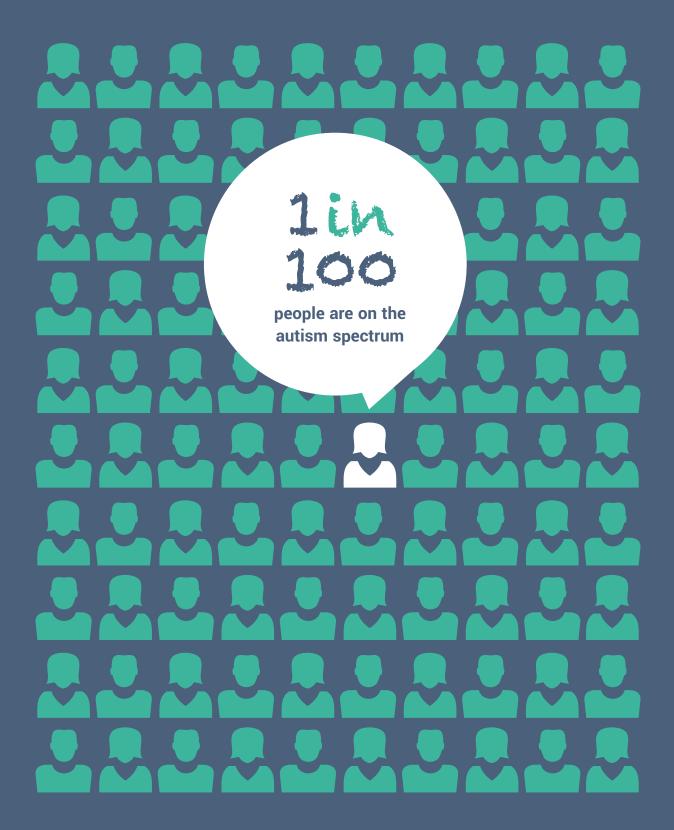
autism&uni

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

Best Practice for HEI managers and senior academics

Marc Fabri Penny C.S. Andrews Heta K. Pukki





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.



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 <u>would f</u>or the average student

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



Project website: www.autism-uni.org

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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.

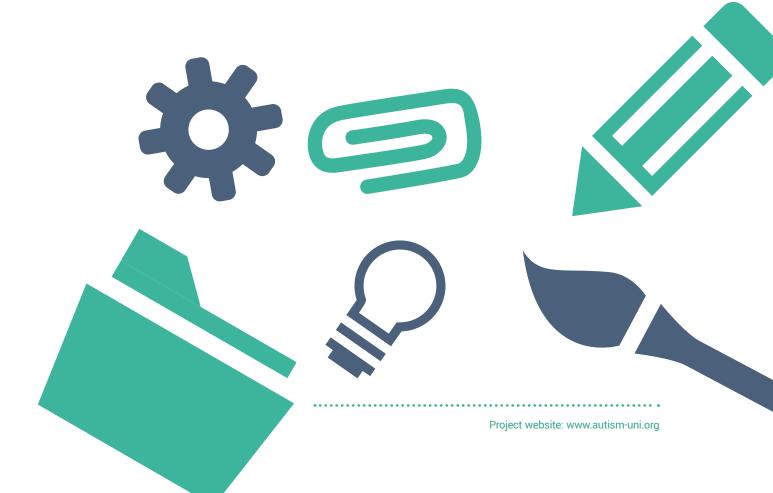
Visit www.autism-uni.org/toolkits to find out more.



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Project website: www.autism-uni.org
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fellow students, because I don't want preconceptions affecting how they see me. I'd rather be a 'mysterious guy' than autistic." "I don't tell my

(student, Netherlands)

Project website: www.autism-uni.org

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.

assistive software on all university computers, or for individual use

special arrangements in student

assessment and support plans by

extra time and a separate room in exams

permission to use laptop computers to

clarification of ambiguous wording

by an assistant in exams and study

university disability teams

type written exams

reduced tuition fees

accommodation

assignments

personal mentoring or coaching

and conveying information about the student's needs to academic staff individual or group sessions with study advisors specialising in autism

including extra time allocated to planning,

extra involvement by study advisors,

- alternatives to or special arrangements
- maps, written directions and other support
- all lecture slides provided in advance
- to help with finding study locations

- permission to record lectures

- designated seats, computers etc.

in lecture halls and classrooms

for group work and oral presentations

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

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

About this guide

in 2014.

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



"A lot of the help that is available is not mentioned at all [during induction], until you are 'on their system' as being on the spectrum. Through disclosure I was able to hear about a biweekly meeting of students who were on the spectrum who meet up to discuss everything from the possibility of a time machine, general elections to different types of tea.

Alongside this I was able to attend a course on employment targeted for people who were autistic. These are not particularly well advertised (if at all) so through disclosing I have emails informing me of these things."

(former student, UK)

Best Practice for HEI managers and senior academics

Background

Diagnosis and disclosure

There is evidence that some students know they are autistic but choose not to declare it (Baines, 2012; Davidson and Henderson, 2010; Huws and Jones, 2008). This can be for a variety of reasons including not identifying as disabled, believing they are not entitled to support or wanting to fit in with their peers. Further, a large number of students with an autism spectrum condition have not been diagnosed by the time they start university, especially female and gender non-conforming students.



In the UK and the Netherlands, about 0.3-0.4% of undergraduate students declare an autism spectrum condition. In other countries, the data may not be collected or the numbers may be even lower

Sources: HESA (2013), Broek et al (2012)

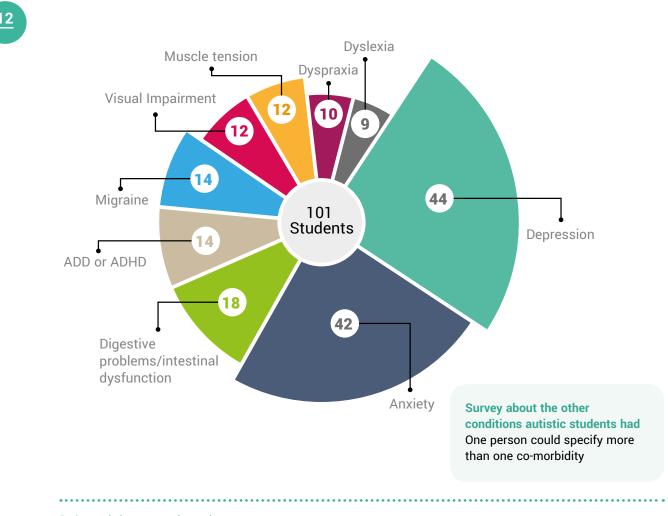
"I feel reluctant to share my problems because in the past my fitness to study' has been questioned. I have university is the right environment for me."

Beyond the stereotypes

Participants in the Autism&Uni mapping exercise 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, 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.

The literature describing autistic students often presumes that autism and perhaps associated learning difficulties and mental health conditions are the only or predominant issues affecting their success in higher education. However, autistic students can experience multiple factors affecting their university experience.



Why is this a problem?

It is difficult for universities to identify the needs of students who do not declare their disability or 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 would benefit from. 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.

"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)



In the UK, while Disabled Students Allowances are common, they are only available to autistic students who have sufficient evidence of their diagnosis. If students do not tick the relevant box on the UCAS form to notify the HEI of their disability, they are unlikely to receive much information about disability support.

The benefits of ticking this box, applying for DSA in good time and so on need to be promoted regularly to ALL potential applicants and need careful wording so that those who don't identify with words like "disabled" will find the information.

HEIs should also make it easy for students to disclose a disability or condition at any time during their studies. There needs to be a clear, simple and well-promoted process for students to do this.

For a HEI to be compliant with the Equality Act, they have an anticipatory duty to put reasonable adjustments in place before students ask for them, and the ideas in the next section and the Takeaways will help an institution to do this.

Many of the ideas we talk about in the next section and the Takeaways can be put in place quickly to the benefit of all students, with or without a diagnosis of autism.

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.

Often autistic students do not have any support in place at the start of their course. Even where support is available from their institution, other organisations, their local area or central government, and they can prove eligibility, they may not have had any help to apply for this nor did they know that it was open to them.

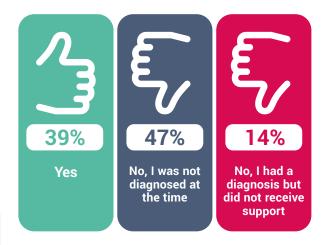
It is good practice to encourage students to apply for support well before they arrive at university, and then to agree and put in place this support for the time the student starts their course of study.

"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."

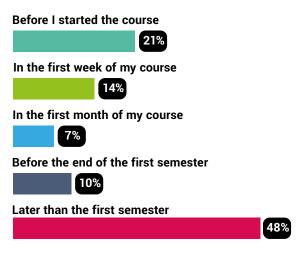
(former student, UK)

Support should be repeatedly and widely advertised to all students, explaining what is available and who can apply. Disability advisors can help students with their applications for support, but only if students know they are there and that autistic students are eligible to receive appropriate support. It is particularly important to start well in advance in a system where the HEIs themselves offer no assessment services. If the student's paperwork is not in order when they arrive, there may be delays because health care services are slow to provide assessment. Some of the delay in getting support in place may also be due to the relevant organisations being very busy at the start of the academic year.

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



For those who did get support, when was that in place?



In the UK and the Netherlands, students can apply for support when confirming a university and a course to study - even if their choice of university changes later on. In the Finnish and Polish systems, they should start talking to a disabled students' ombudsman or accessibility coordinator around the time they apply to university, asking about student services, and submitting formal applications for adjustments. At the same time they should be approaching state or local authorities for services and benefits.

Interventions that benefit all students

Autistic students are generally expected to adapt to the university environment, and not the other way around, be it for practical or economic reasons. The environment is usually designed for 'mainstream' students, and this is understandable as this constitutes the wide majority of the student body.

However, trying to find 'reasonable adjustments' for autistic students can separate them from their peers, increase social anxiety and exacerbate their sense of difference (Madriaga, 2010). A more socially-just approach that understands the desires as well as problems of disabled students would not require students to disclose their differences or seek extra support, and would benefit all students by default.

This is the underlying philosophy of Universal Design for Learning (UDL): to create inclusive learning environments that meet the needs of all students, and to provide multiple opportunities to succeed. See also page 21.

> "Only when I started planning my own schedules, against all recommendations, focusing on one type of subject matter in each period, did I begin to learn effectively."

(student, Finland)

Interventions that benefit all students

Some forms of support can easily be provided for all students at a university - instead of just those who explicitly request it or who have declared a disability. This is likely to improve accessibility and satisfaction across a university's entire student population.

- Some students in our surveys had access to assistive technology like mind mapping software. At Leeds Beckett University (UK), the software most commonly recommended for disabled students is available on all library computers and any student can access it.
- In Finland, Satakunta University of Applied Sciences (in collaboration with the Finnish Association for Autism and Asperger's Syndrome) developed an accessibility checklist for built environments, specifically for people with sensory issues. Initiatives like this can improve accessibility for autistic students.
- Some universities require that all lecture slides and any worksheets or handouts are provided online at least 24 hours in advance of a teaching session (and some record all lectures too). This means individual students do not need to specifically request notes or slides before or after the session.
- 4. At the University of Leeds (UK), the database for room bookings is public and linked to student timetables. The database includes photographs and layout information, text-based directions from the front door of the building and information about the

equipment available. This is useful for lecturers booking a room, but autistic and anxious students also benefit and it reduces the need for support in finding and accessing teaching rooms.

- Timetable and room changes happen, and it is good practice to inform students well in advance about this. Further reminders can be sent closer to the date. Autistic students will need this information as early as possible, and other students may benefit too.
- 6. Many European universities encourage new international and exchange students to arrive a week or so before the rest of the new students to allow them to familiarise themselves with campus and their new home city. Some universities, such as the University of Sheffield (UK), also encourage autistic students to come to university at the same time as the international students, so they can settle in before the other students arrive. This seems to be a better 'phased' entry approach than asking autistic students to attend a residential summer school in the vacation. Offering an early arrival scheme to ALL students who might need more time to get used to campus makes it more accessible to more people without putting a focus on disability.

The sensory environment

Sensory stimulation can be a major issue. Students in the Autism&Uni surveys repeatedly mentioned irritating lighting, crowded spaces and struggled to find quiet places to go when they were stressed.

Senior management can influence the environment students find themselves in by planning and modifying buildings for good acoustics, well-designed directions, more private or separated working spaces, quiet sections in cafeterias, adjustable lighting, visual clarity etc.

These can be reasonably low-cost solutions that benefit all students by reducing stress, without singling anyone out. These measures can provide improved accessibility for those with impaired vision or hearing too. They can also significantly improve a university's public image.

raid navigate t buildings, will upset because he can his way somewher then behave in a unacceptable manner. (parent, Poland)

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Takeaways (good practice to adopt and share)



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

- Ensure that autism spectrum conditions receive the same level of attention and resources as other disability and special needs groups when planning accessibility strategies, disability policies and staff training
- Determine the best internal and external sources of autism expertise that your institution should rely on for information, and create a policy of using these consistently to develop uniform, high-quality practice
- Actively seek out specialist autism organisations near your HEI, request their participation in meetings or commission training for staff
- Find out about the availability of diagnostic and assessment services for autistic adults in your country and region, and adjust your institution's policies accordingly; if necessary, accept assessments by educational professionals or your own student services staff instead of requiring expert medical opinion

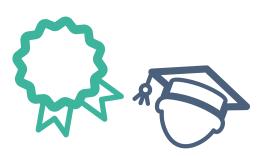
- Involve autistic students in participatory decision-making and design to:
 - plan and design new buildings and services to be accessible for autistic students
 - assess the accessibility of university communications practices including websites, welcome pack information, transition activities and information about disability services
 - assess existing buildings and indoor spaces to identify modifications that can improve general accessibility
 - create and clearly signpost quiet spaces in every area of campus (preferably not multiple purpose rooms)
 - provide picture and text information and directions for all university buildings, ideally down to room level

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- Raise awareness of how making university environments more accessible to autistic students can reduce stress and stigma related to autism, and how this can cut down the need for individualised services which ultimately benefits all students and staff
- Raise awareness of how support and information at the right time can increase retention and graduation of students who would otherwise drop out for reasons unrelated to their academic ability
- During the application and welcome process for new students, promote the benefits of being open about any study requirements or health conditions they may have
- If disability information is not recorded in the application process, include in the information material for new students the details of a named person who students can tell about their autism spectrum condition
- Identify a department or a staff member that students with autism diagnosis can turn to in later stages of their studies, and a named person

in charge of disability support within each department

- Encourage systematic collection of data on the numbers of autistic students in your institution and the effects of reasonable adjustments and support services on their study success, and on progression of autistic students beyond graduation
- Develop strong relationships between all organisations, individuals and teams inside and outside the university that provide support and advice to autistic students
- Publicly celebrate the HE success of autistic students – with their permission; having such role-models is likely to increase applications by more students in the future



Calls to action (what you can do right now)

Survey the accessibility strategies, disability policies and autism/disability related staff training your institution already has in place Encourage support staff to review their perceptions of how effective current support is and invite proposals for improvements

EL.

Identify organisations that can provide training in working with autistic students, and ensure that staff in your institution are aware of this opportunity, especially academic staff and student services Identify departments in your institution that may have an interest in researching autistic students and developing good practice, and discuss with them ways to evaluate and improve current provisions

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
- 3. 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

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
- 5. Navicula Centrum diagnozy i terapii autyzmu w Łodzi www.navicula.pl

Project website: www.autism-uni.org

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
- Autism West Midlands www.autismwestmidlands.org.uk

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> Penny is the Research Assistant for Autism&Uni and a PhD candidate at the University of Sheffield, researching academic social networks. She is also a writer, artist, performer, sprinter and qualified librarian. She was diagnosed with autism while she was a student.



 Heta Pukki, Keskuspuisto Vocational College, Helsinki, Finland

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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Project website: www.autism-uni.org

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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