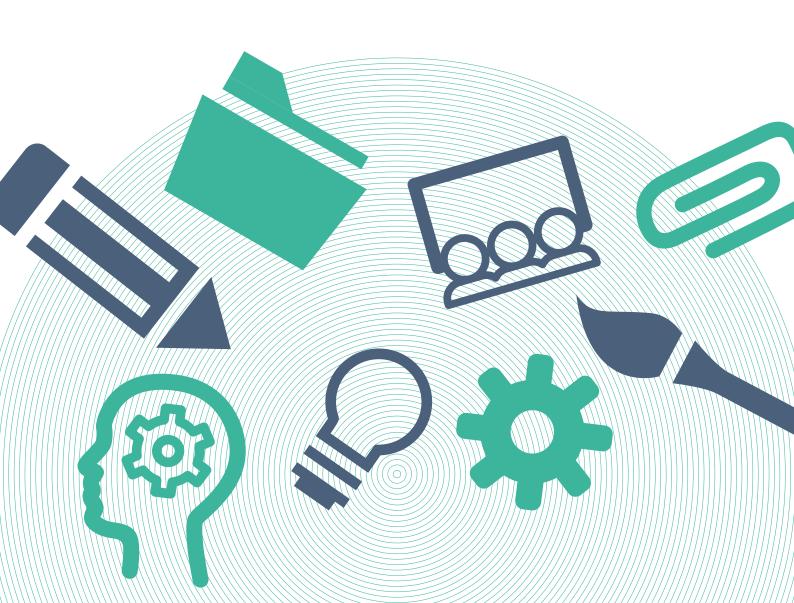
# autism&uni

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

Best practice for professionals supporting autistic students within or outside HE Institutions



# people are on the autism spectrum

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 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.

### 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.



### 03

### **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 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



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.

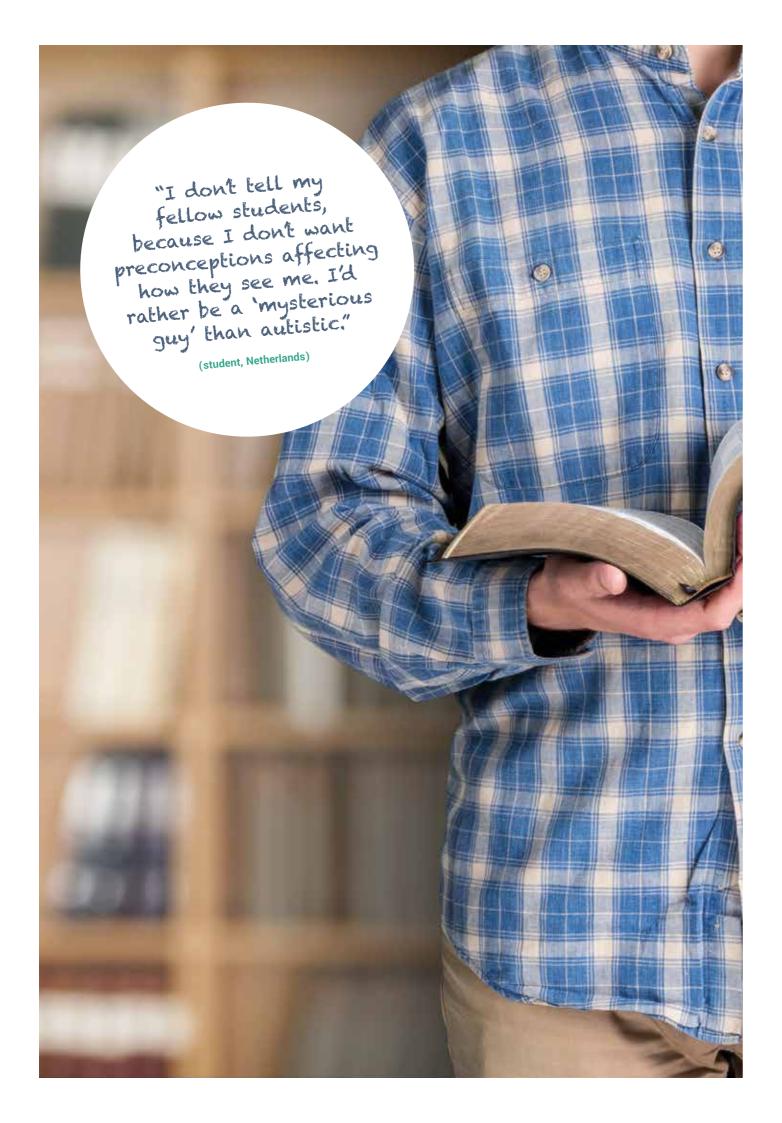


| Introduction   | 01 |
|--|----|
| - About autism   | 01 |
| - About Autism&Uni   | 02 |
| - Challenges faced by autistic students                      | 03 |
| About this guide   | 07 |
| Best practice for professionals supporting autistic students |    |
| within or outside HE Institutions                            | 11 |
| - Background   | 11 |
| - Why is this a problem?                                     | 13 |
| - What can we do about it?                                   | 13 |
| - Takeaways  | 16 |
| - Calls to to action   | 18 |
| Case studies and useful links                                | 23 |
| Acknowledgements   | 26 |
| References   | 28 |
|  |    |









### **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.

### 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.

### Guide 1:

For HEI managers and senior academics

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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.

# Guide 2: For HE lecturers and tutors

autism&uni



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.

### Guide 3:

For professionals supporting autistic students within or outside HE Institutions



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.

### 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



supporting autistic students within or outside HE Institutions

**Best practice for professionals** 

(student counsellor, Finland)

staff members."

"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."

"The greatest challenges are

studies are going poorly and life

management is lacking, as well as

assessing a student's capacity when

sorting out difficulties and conflicts in

social interaction between student and

(former student, UK)

### **Background**

### Diagnosis and disclosure

Many autistic students do not disclose their condition to anyone, 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. 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.

"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)





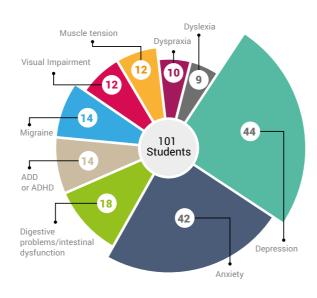
### **Beyond the stereotypes**

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

Many autistic students are high achievers if the right support is in place and not all are friendless loners – students in our surveys found some support patronising as they do not want to be praised just for getting good marks or for having some friends, nor do they want to be compared with other autistic students either positively or negatively as they are individuals in their own right.



Survey about the other conditions autistic students had One person could specify more than one co-morbidity

### **Academic vs social support**

Students and their families told us they felt that social support was too isolated from academic support. Some autistic students receive support from their university for their study requirements, but this does not help with challenges they have that do not directly relate to their learning. Equally, some autistic students receive coaching or mentoring to help with their autism, but the people providing that support do not understand their academic work or how their department works, particularly if the student is a postgraduate and does not have 'basic' problems with their work (like spelling, punctuation, grammar and structure).

# Why is this a problem?

Advisors need to look beyond social and financial support to explore the whole university experience. It is important to bear in mind that specialist autism mentors and coaches, even if provided or funded by the HEI, often have a poor understanding of the current HE context, with little or no knowledge of the study programme, the discipline or the institution.

While general support, such as recorded lectures, provision of lecture slides in advance and so on should be standardised and provided by all lecturers where possible so that all students can benefit, students in our surveys often felt that individual support they were offered, if any, was anything but personalised.

Assistive software, note-takers, additional tutoring, extra time in exams and so on are not always the best fit and students can feel railroaded into accepting what they are being offered while fearing they will receive nothing if they object or reject this later on.

# What can we do about it?

The needs of autistic students should be carefully assessed. It is good practice to have educational professionals and institutions involved in this assessment. However, when these needs are being assessed, too often the focus is on impairments and the perceived weaknesses the student may have.

The purpose of assessment of student needs to be wider – it is also an 'opportunity assessment', allowing the student to build on existing strengths, interests and coping

mechanisms to increase confidence and help them make the most of the university experience. This also enables autistic students with the desire to achieve the highest grades and perhaps go on to postgraduate study to share their aspirations and make sure any support received is a good fit that respects both their difficulties and their ambitions.

It is good practice to monitor and re-assess. Situations change and some students require additional support at later stages, e.g. when trying to do thesis work.

It is also good practice to have assessment centres where uniform assessment practices and a certain level of autism expertise can be guaranteed. Centralisation and standardisation are key aspects of assessment services if any country or HEI wants to offer support equally to all, not just to a lucky few.

Provision of information and services to "non-traditional" students often puts these students into a single 'box': physically disabled, specific learning difficulties, mature, international, LGBT, black and minority ethnic, part-time, distance learners, low income, commuting etc. It is important that websites, printed leaflets and other marketing materials reflect the diversity in all these groups so students can find, access and relate to appropriate information and services where available.

"The [autism
charity] didn't
understand me at all
and was very patronising
and told me I shouldn't
aim so high because
having ASD meant I
couldn't achieve"

(former student, UK)

# 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.

However, 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.

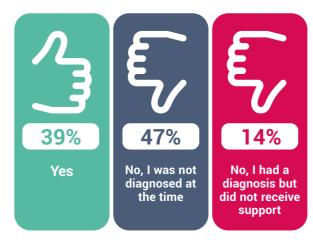
It is good practice to encourage students to apply for support well before they arrive at university, and then to agree and put in place this support for the time the student starts their course of study.

Support should be repeatedly and widely advertised to all students, explaining what is available and who can apply. Often advisors can help students with their applications for support, but only if students know these advisors 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 to start their studies, 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.

Survey data highlighting how many students didn't get support until after the first semester

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



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

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%

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.

### **Early start**

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 who are moving away from home 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.

Students who have attended those sorts of programmes enjoyed them, but our research found that they did not improve outcomes for many of the issues autistic students struggle with, such as how they will get on with the people they will really be living with (even residential schemes do not involve their eventual flatmates when living in halls), socialising with course mates and coping with being on campus when it is busy. The schemes also only involve a very small number of students, whereas early entry, particularly if offered to ALL students who might need more time to get used to campus, is more accessible to more people.

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

"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."



### **Peer mentoring**

The Universidad de Las Palmas de Gran Canaria (Spain) runs a peer mentoring scheme for autistic engineering students (Tobajas et al., 2014). Each student is provided with two peer mentors in their department that they can use for transition support and/or throughout the year. Weekly support is provided. The project has been running successfully for 10 years and information about inclusive teaching and supporting specific individuals is provided for academic staff. The mentors are highly motivated students further on in their degrees who have expressed an interest in helping students on the autism spectrum, and they regularly attend one-to-one meetings with the students and group supervision.

Retention and academic performance improved in students taking part in the scheme, which they rated highly. Peer mentoring schemes exist at other universities, but the Las Palmas scheme is interesting because it connects to the student's peer group and subject of study and removes the division between academic and social understanding that is present in other forms of support.

# **Takeaways** (good practice to adopt and share)



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

- Encourage autistic students to apply for support and arrange an assessment as early as possible; be pro-active in communicating with students about the support available
- Ensure that an assessment covers both the challenges and the positive aspects of autism. If the assessment is done externally or by medical professionals only, consider complementing it with an additional educational assessment:
- assess impairments, challenges, and the need for any services or technological solutions that these require
- encourage students to understand the positive aspects of their autism (that are specific to them) for their academic life and beyond, and their personal strengths
- assess personal coping strategies, strengths and interests.
- Ensure that support arrangements involving mentors, buddies, coaches, note-takers and the like are consistent, i.e. the same person at the same time in the same place; this will reduce anxiety for the student
- When assessing the requirements of students or making decisions about support services, consider possible overlap between HEI and external provision, as well as the possibility of areas not covered by any organisation

- When writing official statements to recommend adjustments and services, provide an opportunity to re-assess the situation in case the suggested interventions are unavailable or turn out not to function as expected
- Develop general practices for regularly reviewing support requirements, using low barrier means such as quick surveys; include input from students, academics, support staff and also parents as stress at university may not be expressed at university but picked up at home
- Ensure students are aware that they do not simply have to work with the support staff they have been allocated – interpersonal relationships do not always work, even on a professional level
- Encourage students to work with you to put together information that can be conveyed to their tutors and lecturers, making this information specific to them and relevant to their study situation
- If you see that provision for a student is divided between several service systems and therefore difficult to manage, ensure that there is a single, clearly identified individual or organisation in charge of overall coordination and keeping all service providers up to date

# If you are working within a HE Institution:

# If you are working outside of HE Institutions:

- Advocate for the adoption of accessible and uniform assessment practices at your HEI, in order to ensure equal treatment for all students
- Use your experience of autistic students' requirements and preferences to improve general accessibility at your institution:
- create information that can be sent to new students in connection with the application and welcome processes
- create picture and text information and directions for university buildings, and advocate for this to be made general practice
- negotiate with administration and faculties to locate and label quiet spaces in buildings and on campus
- suggest these types of action to be included in your institution's official accessibility strategy
- Build up a staff network to support autistic students outside disability/accessibility teams and student services, covering as many teams and departments as possible to provide joined-up support that is anticipatory, rather than reactive

- Develop good relationships with HEIs, e.g. by setting up regular network meetings with relevant HE staff; if HE staff are not available, ensure that they receive information about decisions affecting students
- Actively offer training to improve awareness and skills among HE staff
- Act as an independent advocate for autistic students when there appears to be a shortage of this kind of support from within the university

"There should
be a much greater
information exchange
between [autism support
staff and academics] so that
tutors are better informed
and understand some of
the problems students with
autism have to face up to
each day."

(student, Netherlands)

# Calls to action (what you can do right now)

ST)

Involve the student
in all discussions and
decisions about their study
requirements; communicating
with the student is not only
good practice, it is mandatory





Actively engage with academic staff about how learning to work better with autistic students would also provide opportunities to improve the experiences of students generally







Critically examine the support and information offered to autistic students, and compare it to descriptions of good practice from other HEIs and countries; review it regularly with input from students and recent graduates, including those who no longer receive services



Encourage students to review
the support they receive
regularly, making it clear they
will not be left without support
if they are critical of their
current provision



ST)

If a student chooses not to renew services in subsequent years of a course, find out why



Encourage or start the practice of collecting data about the numbers of autistic students, the support they receive and their opinions of its usefulness, especially if this has not been done before

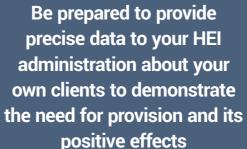


Be aware that autistic students may find some commonly used terminology inaccurate, insulting or discouraging, and that preferences may vary both individually and depending on country and region; consider the tone you set by using 'challenge' instead of 'difficulty', 'limitation' or 'difference' instead of 'disability', 'autistic characteristics' or 'autistic condition' instead of 'autistic disorder', 'support' instead of 'treatment'

### If you are working within a HE Institution:



Request and undergo training in supporting autistic students in the HE environment





If suitable training is not available, make a request to a relevant department within your institution or to an external organisation with autism expertise that they start creating such training



Discuss training requirements with other staff members, e.g. tutors and lecturers, who work with autistic students If you have already had training, share your knowledge with colleagues

### If you are working outside of HE **Institutions**:



Proactively offer your expertise to HE staff about how learning to work better of students generally

# staff and actively engage with academic with autistic students would also provide opportunities to improve the experiences

### **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)





# 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**

- 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



### M

### **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**

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

www.stumass.nl

 Landelijk Netwerk Autisme www.landelijknetwerkautisme.nl

### **Useful Links**

- 1. Fundacja Jaś i Małgosia w Łodzi www.jim.org/fundacja
- Fundacja Synapsis w Warszawie synapsis. org.pl
- 3. Stowarzyszenie Dalej Razem w Zielonej Górze

www.dalejrazem.pl

4. Stowarzyszenie Uczymy się żyć razem w Opolu

www.autyzmopole.pl

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



### **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





### **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**

- 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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worker and NGO activist.

### We thank the following people for their helpful contributions and comments:

Antti Aavikko, Jan-Mikael Fredriksson, Daria Modrzejewska, Amanda Szukalska, Paul Quantock, Natasha Stash, Alejandro Montes García, María Merino, Miguel Lancho, Christian García, Roy Houtkamp, Harriet Cannon, Kate Dean, Kate Myers, Matt Tucker, Danny Gallacher, Steven Chamberlain, Diane McClymont

The Autism&Uni (AUTHEW) 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.

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"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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The Autism&Uni (AUTHEW) 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.

Funding ref 539031-LLP-1-2013-1-UK-ERASMUS-ESIN

