

autism&uni

D2.3 Mapping Survey Report

By Marc Fabri and Penny Andrews, Leeds Beckett University, March 2015

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1 Background

The Autism&Uni project (www.autism-uni.org) aims to support students during the critical transition periods from leaving secondary education and applying to university through to arriving and settling in at university. It will do this through an interactive toolkit that provides students with strategies for overcoming the challenges they typically encounter, and through the sharing of best practice amongst professionals who support autistic students or influence policy and regulations that affect autistic students.

Work Package 2 aimed to conduct a comprehensive mapping exercise in all partner countries, investigating current provision, aspirations and means by which autistic students are supported. The main research instrument was a set of questionnaires, developed by the project partners and piloted with a small number of autism professionals and autistic people.

It was important to conduct this mapping survey in order to fully understand, through first-hand accounts, what helped, influenced or prevented young people on the autism spectrum to fulfilling their ambition of Higher Education success.

Leeds Beckett University, as Work Package leader, designed the research methodology and draft versions of the questionnaires. All partners then collaboratively refined the questionnaires over a period of several months in Spring 2014. The mapping survey itself took place between 3 September 2014 and 5 January 2015.

This report summarises the findings from the mapping survey. It should be noted that the mapping survey was not the sole basis for subsequent project deliverables (the creation of an online toolkit and a best practice guide). Survey results were complemented by the findings of a literature review, also carried out in 2014 (see separate project report D2.1).

2 Research aims and objectives

The overall research aim for the mapping exercise was articulated in the funding application:

"To conduct a mapping exercise, in 5 countries, to investigate current provision and aspirations and means by which students with ASD are supported"

The specific research objectives guiding the survey process were:

1. Identify good practice in support for autistic students
2. Identify gaps in support for autistic students
3. Understand aspirations of autistic students
4. Understand reasons for under-representation
5. Identify design preferences held by the target audience

3 Executive Summary of results

Key challenges faced by autistic students

1. 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
2. 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
3. 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
4. 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
5. 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

Good support practice found in the institutions surveyed, or as reported by students

- 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

3.1 Suomi

Autismin kirjoon kuuluvien opiskelijoiden kohtaamia haasteita

1. Asianmukaisen tuen puute
 - Asianmukainen tuki puuttuu opintojen alusta lähtien
 - Huomiota kiinnitetään autismiin liittyviin toimintarajotteisiin, eikä niinkään vahvuuksiin
 - Kohtuullisia mukautuksia, autismin kirjoon kohdistuvia erityispalveluja ja henkilökohtaisia tukitoimia ei saa johdonmukaisesti
2. Sosiaalinen ja fyysinen ympäristö
 - Vaikeus ymmärtää kirjoittamattomia sosiaalisia sääntöjä vuorovaikutuksessa opetushenkilökunnan ja muiden opiskelijoiden kanssa
 - Vaikeus sietää taustamelua, valaistusta, väkijoukkoja tai muuta opiskeluympäristöön liittyvää aistikuormitusta
 - Vaikeus käsitellä uuteen asuinpaikkaan usein liittyvää sosiaalista eristyneisyyttä.
3. Epärealistiset odotukset
 - Ei selkeää käsitystä siitä, millaista korkeakoulussa opiskelu todellisuudessa on
 - Ei selkeää käsitystä opiskeltavien aiheiden ja kurssien sisällöistä
 - Odotukset omaa suoriutumista kohtaan ovat yhtä korkealla kuin toisen asteen opinnoissa
 - Liian optimistiset käsitykset opiskelutoverien kiinnostuksen kohteista ja omistautumisesta opinnoille
4. Tehtävänantoihin liittyvät haasteet (vaikka itse asiasisältö olisi hyvin hallussa)
 - Vaikeus ymmärtää monitulkintaisia ja avoimeksi jääviä tehtävänantoja
 - Puutteellinen kyky hahmottaa, minkä takia jokin asia on tehtävä
 - Vaikeudet oman työn suunnittelussa ja tarkistamisessa
 - Epävarmuus siitä, kuinka paljon aikaa annetun tehtävän suorittaminen vaatii
5. Siirtymävaihe aikuisuuteen on haastavampi kuin keskiverto-opiskelijalla
 - Muuttaminen lapsuuden kodista omilleen tuottaa vaikeuksia
 - Ajanhallinta ja uusien rutiinien luominen on tavallista vaikeampaa
 - Omien etujen ajaminen on vierasta

Eurooppalaisissa korkeakouluissa on käytössä muun muassa seuraavanlaisia palveluja ja mukautuksia autismin kirjoon kuuluville opiskelijoille

- Tarvearviointi- ja tukisuunnitelmia, joita korkeakoulujen vammaispalvelutiimit kokoavat
- Henkilökohtaista mentorointia tai valmennusta
- Erityistä tukea opinto-ohjaajilta ja opiskelijapalveluilta, mukaan lukien ylimääräistä aikaa opintojen suunnitteluun ja opiskelijan tarpeita koskevan tiedon välittämistä opetushenkilökunnalle
- Henkilökohtaisia tai ryhmätapaamisia autismin kirjoon kuuluvien opiskelijoiden tarpeisiin erikoistuneiden opinto-ohjaajien tai opintopsykologien kanssa
- Vaihtoehtoisia tapoja suorittaa kursseja, jotka sisältävät ryhmätöitä tai suullisia näyttöjä
- Ylimääräistä aikaa ja erillisiä huoneita tenttejä varten
- Mahdollisuus käyttää tietokonetta tenttivastausten kirjoittamiseen
- Mahdollisuus käyttää tukihenkilön apua monitulkintaisten tenttikysymysten tai tehtävänantojen selventämiseksi
- Kaikkien luentomateriaalien pitäminen opiskelijoiden saataville etukäteen
- Mahdollisuus äänittää luentoja
- Nimettyjä istumapaikkoja ja tietokoneita luentosaleissa ja luokkahuoneissa
- Apuohjelmistoja asennettuna oppilaitoksen tietokoneille
- Karttoja, kirjallisia ohjeita tai muuta apua suunnistamiseen korkeakoulun alueella ja rakennuksissa
- Alennusta lukukausimaksuista
- Erityisjärjestelyjä asumispalveluissa

3.2 Nederlands

Uitdagingen voor autistische studenten

1. De sociale en fysieke omgeving
 - Problemen bij het oppikken van ongeschreven sociale regels in het contact met docenten en medestudenten.
 - Problemen met het tolereren van achtergrondgeluid, verlichting, drukte of andere sensorische aspecten in een universitaire omgeving.
 - Omgaan met het sociale isolement dat vaak samengaat met het wonen in een nieuwe omgeving.
2. Gebrek aan goede ondersteuning
 - Het ontbreken van de toegang tot goede ondersteuning direct bij de start.
 - De focus op de tekortkomingen bij autisme, in plaats van op de sterke punten die de student heeft.
 - Het gebrek aan consistentie in redelijke aanpassingen, autisme-specifieke en persoonlijke ondersteuning.
3. Onrealistische verwachtingen bij de student
 - Wat studeren aan een universiteit echt is.
 - De inhoud van een studieonderwerp of opleiding.
 - Presteren op hetzelfde hoge niveau als in het middelbaar onderwijs.
 - De interesses en toewijding van medestudenten.
4. Uitdagingen met betrekking tot beoordeling (zelfs wanneer ze het onderwerp beheersen)
 - Moeilijkheden met het goed interpreteren van ambigue en open opdrachten.
 - Niet begrijpen waarom iets gedaan moet worden.
 - Problemen met planning van de studie en met correcties.
 - Onzekerheid bij het inschatten van tijd die gespendeerd moet worden aan een opgegeven taak.
5. De overgang naar volwassenheid vergt meer inspanning dan voor een gemiddelde student
 - Voor de eerste keer verhuizen.
 - Planning van tijd en het ontwikkelen van routines.
 - Niet gewend zijn voor zichzelf op te komen

Sommige Europese HOI voorzien al in combinaties van de volgende ondersteuning en aanpassingen

- Toets- en ondersteuningsvormen door teams voor gehandicapten aan de universiteit.
- Extra tijd en afzonderlijke kamers tijdens examens.
- Toestemming om laptops te gebruiken bij een schriftelijk examen.
- Uitleg van ambigue bewoording door een assistent tijdens examens en bij studieopdrachten.
- Gereduceerd inschrijfgeld.
- Speciale arrangementen voor studentenhuysvesting.
- Ondersteunende software op alle computers op de universiteit, of voor privé gebruik.
- Privé mentoren of coaches.
- Extra betrokkenheid van studieadviseurs, inclusief extra tijd voor planning en het overbrengen van informatie aan de staf van de universiteit over zaken waar autistische studenten behoefte aan hebben.
- Individuele of groepsessies met studieadviseurs die gespecialiseerd zijn in autisme.
- Alternatieven of speciale arrangementen voor groepswork of mondelinge presentaties.
- Plattegronden, geschreven richtingaanwijzingen en andere ondersteuning als hulp bij het vinden van studielocaties.
- Het vooraf verstrekken van alle slides die in een college gebruikt worden.
- Toestemming om lessen op te nemen.
- Vaste plaatsen, computers etc. in collegezalen en klassen.

3.3 Polski

Wyzwania, z jakimi muszą się zmierzyć studenci autystyczni

1. Środowisko społeczne i fizyczne
 - trudności w przyswajaniu niepisanych zasad społecznych w trakcie interakcji z dydaktykami i studentami
 - trudności z tolerowaniem hałasu w tle, jaskrawego oświetlenia, tłumów i inne aspekty sensoryczne środowiska uniwersyteckiego
 - radzenie sobie z izolacją społeczną, która często związana jest z zamieszkaniem w nowym środowisku
2. Brak odpowiedniego wsparcia
 - brak dostępu do odpowiedniego wsparcia od samego początku
 - skoncentrowanie się na „deficytach” autyzmu bardziej niż na mocnych stronach studenta
 - brak spójności w rozsądnych dostosowaniach, usługach dedykowanych spektrum autyzmu jak i wsparciu osobistym
3. Nierealistyczne oczekiwania studenta
 - jak wyglądają studia na uniwersytecie
 - treści studiowanego przedmiotu lub kursu
 - osiągnięcie tak samo wysokich wyników co w szkole wyższej
 - zainteresowania innych studentów i poświęcenie
4. Wyzwania związane z oceną (nawet przy doskonałym opanowaniu przedmiotu)
 - brak zrozumienia, dlaczego coś powinno zostać wykonane
 - trudności w planowaniu procesu studiowania i powtórzeń
 - niepewność, jak wiele czasu należy poświęcić na określone zadanie
 - trudności z właściwą interpretacją zadań otwartych i niejednoznacznych
5. Wejście w dorosłe życie wymagające więcej wysiłku niż w przypadku przeciętnego studenta
 - wyprowadzka z domu po raz pierwszy
 - zarządzanie czasem i ustalanie porządku dziennego
 - brak doświadczenia w skutecznym ubieganiu się o swoje prawa

Niektóre z instytucji szkolnictwa wyższego świadczą już następujące usługi i wprowadzają modyfikacje

- plany oceny i wsparcia opracowywane przez uniwersyteckie zespoły ds. osób niepełnosprawnych,
- dodatkowy czas i oddzielne sale na egzaminy,
- zgoda na korzystanie z laptopów podczas egzaminów pisemnych,
- wyjaśnienie niejednoznacznych sformułowań przez asystenta na egzaminie i przy realizacji zadań,
- zmniejszenie opłat czesnego,
- specjalnie urządzenie miejsca zakwaterowania,
- zainstalowanie oprogramowania wspierającego na wszystkich komputerach na uniwersytecie, lub do indywidualnego wykorzystania,
- osobisty mentoring lub coaching,
- dodatkowe zaangażowanie przez doradców, włączając dodatkowy czas poświęcony na planowanie, przekazywanie informacji o potrzebach studenta pracownikom uniwersytetu,
- indywidualne lub grupowe sesje z udziałem doradców specjalizujących się w autyzmie,
- alternatywne lub specjalne ustalenia dotyczące pracy w grupach lub prezentacji ustnych,
- mapy, spisane instrukcje i inne wsparcie związane ze znalezieniem miejsc na uniwersytecie,
- wcześniejsze udostępnienie slajdów z wykładów,
- udzielenie zgody na nagrywanie wykładów,
- wyznaczone miejsca, stanowiska komputerowe etc. w salach wykładowych i zajęciowych.

3.4 Español

Desafíos a los que se enfrentan los estudiantes con autismo

1. El entorno social y físico
 - dificultad para captar las reglas sociales no escritas en la interacción con los tutores y compañeros de clase
 - dificultad para tolerar el ruido de fondo, la iluminación, las aglomeraciones u otros aspectos sensoriales del entorno universitario
 - gestión del aislamiento social que, a menudo, está asociado a la vida en un entorno nuevo
2. La falta del apoyo adecuado
 - falta de acceso a una atención adecuada desde el principio
 - énfasis en las «deficiencias» del autismo, en lugar de en las cualidades que aportan los estudiantes
 - falta de consistencia en adaptaciones razonables, servicios específicos del autismo y apoyo personal
3. Expectativas poco realistas
 - realidad del estudio universitario
 - contenido del objeto de estudio o curso
 - rendir al mismo nivel —elevado— que durante la educación secundaria
 - intereses y dedicación de los compañeros
4. Retos en materia de evaluación (incluso cuando el estudiante domina la materia)
 - dificultades para interpretar correctamente los enunciados ambiguos de las tareas asignadas
 - incompreensión de por qué hay que hacer algo
 - dificultad para planificar los estudios y la revisión
 - incertidumbre sobre cuánto tiempo dedicar a una tarea asignada
5. La transición a la vida adulta requiere un mayor esfuerzo que el que necesitaría un estudiante promedio
 - mudarse lejos de casa por primera vez
 - gestión del tiempo y establecimiento de rutinas
 - desconocimiento de la defensa eficaz de uno mismo

Algunas instituciones europeas de educación superior ya ofrecen combinaciones de los siguientes servicios y adaptaciones

- planes de evaluación y apoyo por parte de equipos de la universidad especializados en discapacidad
- más tiempo y un aula separada para los exámenes
- permiso para usar portátiles para poder redactar los exámenes escritos a ordenador
- aclaración de los enunciados ambiguos por parte de un auxiliar durante los exámenes y las tareas de estudio
- matrícula reducida
- organización especial del alojamiento para los estudiantes
- software de asistencia en todos los equipos de la universidad o de uso individual
- tutorías u orientación personal
- participación adicional de los asesores de estudio, incluido tiempo adicional asignado a la planificación y a la transmisión de información sobre las necesidades del estudiante al personal académico
- sesiones individuales o en grupo con asesores de estudio especializados en autismo
- organización alternativa o especial para trabajos en grupo y presentaciones orales
- mapas, direcciones escritas y otro tipo de apoyo para ayudar a encontrar lugares de estudio
- entrega por adelantado de todas las diapositivas del curso
- permiso para grabar las clases
- asientos designados, equipos etc. en salas de conferencias y aulas

4 Disclaimer

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5 Questionnaire Design Process

In February 2014, partners were invited to forward questionnaire content ideas and relevant resources by email to the work package leader. These needed to relate to the research aims and objectives identified above. This method was chosen to avoid the exclusion of tools that were relevant, but did not fit into any template. The partners wanted to keep an open mind and select measuring tools on their individual suitability, not on their structure.

All five partners responded. In addition to the initial responses, a number of discussions started on the project's social media platform about the applicability of certain tools in different countries, and about the scope of the mapping exercise. These contributed usefully to this report and the survey design.

Leeds Beckett University collated responses and created draft versions of the questionnaires.

5.1 Resources provided by partners

- Summary report of ASILeSP - Autism Specific Interactive Learning Software Packages Project
- Rethinking HE for students with ASD slides
- AHEADD website
- Disabled World website
- Guía de Atención a la Discapacidad en la Universidad (Care Guide to Disability at University) – guide to adaptations available at Spanish universities
- Leeds Met Disability Stats document
- NAS Employment blog posts
- Foundation for People with Learning Disabilities booklet
- Autism Goes to College forum documents
- BBC report on autism summer school at Bath
- BBC report on Cardiff mentor scheme
- Teaching pre-university skills materials
- Top Tips for Asperger Students book
- Spanish article about vocational training
- Universidad Mexico student activity preferences webpage
- Test de Holland website
- University interests test
- Junta de Andalucía website
- TEAEdiciones website
- Professions and employment website
- University of Pennsylvania website
- Going to College website
- DWP website
- Autism journal article
- Autism employment survey
- Guide to assessing college readiness

5.2 Other sources consulted

- Personal experience of autistic research assistant
- Disability Rights UK Into Higher Education guide, factsheets & adjustments list
- National Autistic Society applying for university guidance
- Asperger Home Education website
- UCAS website
- University of Melbourne website
- Department of Health working report
- Ofsted survey of progression
- IRISS transition to adulthood report

5.3 Emerging criteria

These responses and additional resources led to some basic criteria likely to affect success in HE:

1. Intervention and support from institution
2. Intervention and support from friends/family
3. Information availability
4. Eligibility for support (at school and at university)
5. Life skills/Individual attributes – self-advocacy, self-assessment of what is easy/difficult, what constitutes “safety” at university
6. Institutional knowledge/expertise about autism

Project partners also wanted to find out about other important factors that would affect the success of the student at university and the success of the project itself, namely:

- Study choice – and how it was informed
- Technology devices owned
- Level of comfort around technology

5.4 Groups to target with the survey

Several target groups and research methods were initially identified:

#	Target group
1.	future HE students with autism, i.e. those currently applying to, or preparing for, university, whether at school, in further education colleges, home-schooled or specialist institutions
2.	current HE students with autism, i.e. those currently studying at university
3.	HE graduates with autism, i.e. those who have obtained a HE degree
4.	HE dropouts with autism, i.e. those who have withdrawn from a HE degree programme
5.	Parents or carers of school-aged children with autism
6.	School teachers or mentors of school-aged children with autism
7.	Disability advisors at HE institutions or whoever is responsible for pastoral care of students with autism
8.	Autism organisations and charities
9.	Autism professionals and others working with autistic children, such as independent disability assessors

For each of these target groups, we collated a set of guiding questions that will form the basis of questionnaires, interviews or other means of information gathering. To provide rich data, questions were generally phrased in an open manner, using who / what / when / where / why.

5.5 Terminology around the word autism

We acknowledge that there are differences in terminology when referring to autism, and that this is a matter of preference rather than a question of using the right or wrong format.

Parents, carers and academics tend to prefer the 'person first' terminology, as in "the person with autism", in an attempt to separate the person from the condition. Autistic people themselves often prefer to say "autistic person" or "I am autistic", seeing autism as a fundamental part of their personalities, and not as a condition or disorder.

Throughout the English-language surveys, the following terminology was used. Other partners used their own discretion when translating the questionnaire items:

1. Surveys predominantly targeted at autistic people: "autistic person"
2. Surveys predominantly targeted at non-autistic people: "person with autism"

5.6 Ethical approval

All questionnaires included a disclaimer relating to research ethics. Ethical approval was granted by Leeds Beckett University (Leeds Metropolitan University at the time the ethics application was submitted), and partners were advised to seek their own ethical approval where relevant if they conducted studies in their home countries.

5.7 Validity considerations

Sample size

In order for survey results to be suitable for statistical analysis a minimum sample size of 25 responses for each questionnaire is the target. Predicting a response rate of 10%, partners pledged to send each questionnaire to **at least 250 targeted participants**.

Question Bias

Wording of questions was deliberately kept concise and unambiguous. This is particularly important for questionnaires targeting autistic people due to a tendency to take questions very literal. Word limits were stated for all open questions to encourage responses with sufficient detail, whilst at the same time avoiding overly detailed responses. Double-barrel questions were avoided, as were leading questions and questions involving negatives or double negatives.

Language Bias

When translating questionnaires into other languages it is critical that the meaning of each question stays intact. If this does not happen, responses cannot be compared with each other and the results from that language version become unusable. However, partners were permitted to adapt the wording to suit the respective country context, and on occasion the sentence structure was changed to keep the meaning but say things in a more appropriate way.

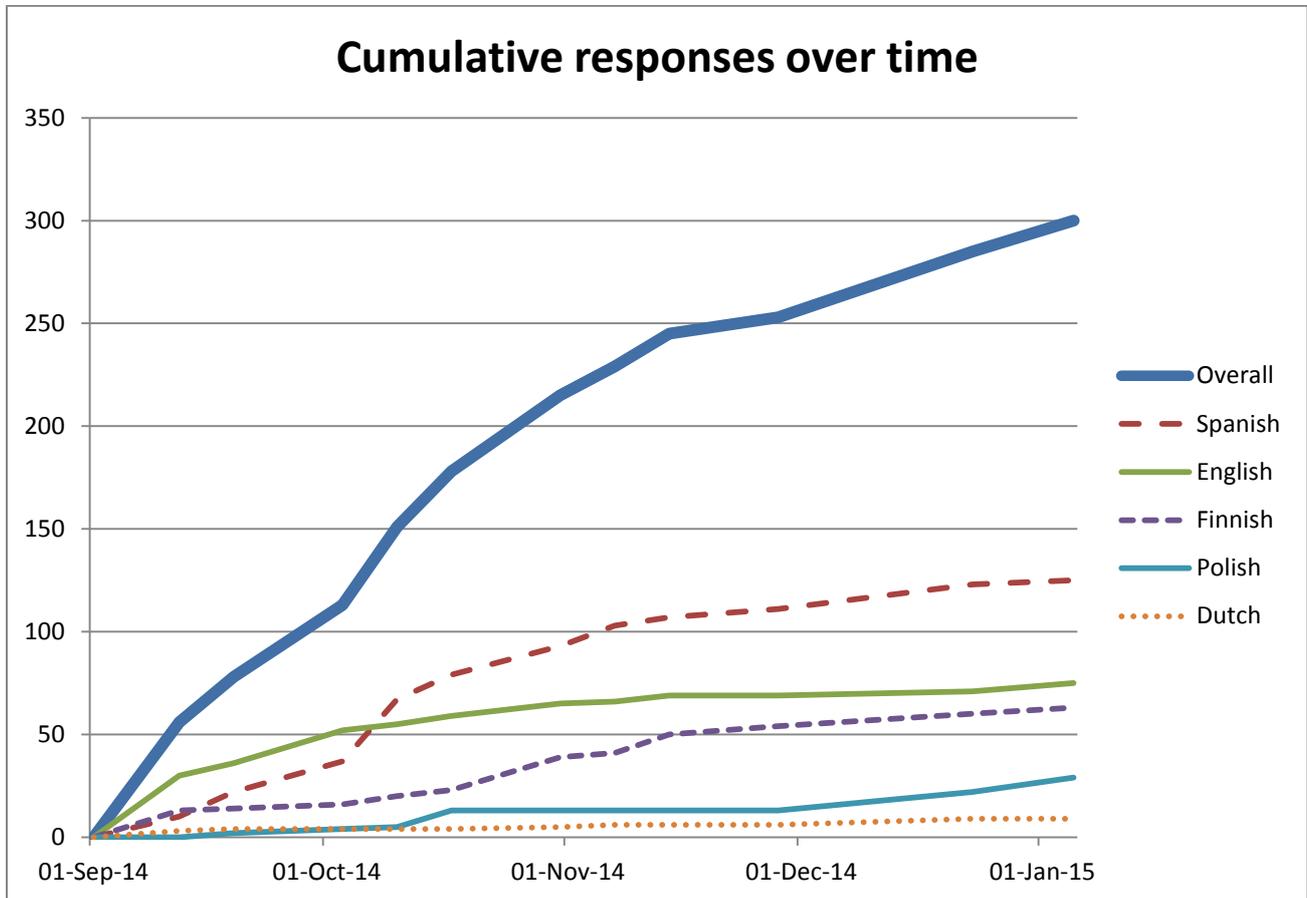
6 Final Questionnaires

Following several revisions and merging of questionnaires, the final set of questionnaires targeted the following groups (see table below). Questionnaires were available in the 5 partner languages, translated by the partners. Printable reference versions of the English language questionnaires are available on the project website at www.autism-uni.org/outputs.

#	Questionnaire
1.	Preparing for HE Future HE students with autism (aged 16+), i.e. those currently applying to, or preparing for, university, whether at school, in further education colleges, home-schooled or specialist institutions
2.	Current Students Current HE students with autism, i.e. those currently studying at a HE institution
3.	Previous Students People with autism who previously attended a HE institution. This may be HE graduates who successfully completed their course, or those who dropped out from their studies.
4.	Parents and Carers Parents or carers of young people (aged 14-30) with autism who may go to university, currently are at university or have been to university
5.	Teachers and Mentors School teachers or mentors of school-aged children with autism (aged 16+)
6.	HE Institutions Staff working within HE institutions on teaching, advising or supporting students with autism
7.	Autism Organisations and Professionals Charities, national or regional bodies, parent groups, Autism professionals and others working with autistic children and young adults, including independent disability assessors
8.	First Person Story First Person account of experiences
9.	Third Person Story Third person account of experiences

7 Response Rates

The survey was launched 3 September 2014 and closed 5 January 2015. 300 responses were received overall. The graph below illustrates response rates over time.



By the end of the survey, 300 responses were received. Of these, 20 had to be excluded from the dataset due to invalid content. Most were excluded because of the age of the child in question (14 was the minimum age). The table below shows the final distribution of responses by questionnaire and by language:

	English	Dutch	Finnish	Polish	Spanish	TOTAL
Q1 – Not yet at uni	3	0	6	9	12	30
Q2 – At uni	17	2	16	0	12	47
Q3 – Left uni	23	3	18	0	10	54
Q4 – Parents & Carers	10	0	8	4	26	48
Q5 – Teachers	4	1	1	10	10	26
Q6 – HE institutions	10	2	3	2	10	27
Q7 – Autism orgs	6	1	3	2	20	33
S1 – First person story	2	0	5	0	3	10
S2 – Third person story	0	0	1	0	5	6
TOTAL	75	9	61	27	108	280

8 Results from questionnaires

8.1 Student responses (Q1-3)

Overall 131 autistic students took part in the survey (30 who had not yet started university, 47 currently at university and 54 previous students). The gender balance was 56.5% female, 37.5% male, and 6% identifying as "other". The average age was 22 for those not yet at university, 26 for those at university, and 35 for those who had left university. Around 80-90% had a medical diagnosis of autism, with a recent increase in diagnoses from educational staff rather than medical professionals.

8.1.1 Choosing university and a subject

Students across the board were likely to say they loved studying and needed the degree to get a job they had in mind. Interest in research also featured strongly. For the older students who had left university, family pressure was strong (41%), whilst the younger generation reported this to be less of an influence (17%). Many students talk about university as a “safe” place where they are not pressured to get a job, bullying is not tolerated (if their autism is disclosed) and they can be themselves without judgement or criticism. Most participants did extremely well in their studies if they completed them – they were among the best students.

A surprisingly high number of students chose to go to university to ‘escape’ from their home situation, either because their family situation was bad or because they really wanted to move away from home to be independent. Some chose courses specifically because they were a long way from where their family lived. We cannot assume that all students have good relationships and support at home or that parents have a strong influence on their lives.

Students with autism pick a wide range of subjects to study, with many choosing subjects that may be considered 'unsuitable' or challenging, such as philosophy, religion, languages, art, literature, writing, humanities, social science, health, communications, history and business administration. While there are plenty of students picking the 'stereotypical' STEM subjects to become physicists, engineers, mathematicians and computer scientists, they do not actually form the majority.

Most students choose their subjects based on their hobbies/interests, many describing themselves as having a passion for their subject, as well as of course good previous grades and for some work experience. Family and friends are not that influential in comparison. Some chose subjects their parents wanted them to do at first and either dropped out and chose something else or later did postgraduate study that was closer to their interests. Being dependent on parents made some feel bad.

There are problems around “big picture thinking” – understanding why they are studying a particular module and how it fits into the whole degree, what they are supposed to be doing outside of lectures, what it will lead to and when to prepare for the next stage of the course or their life (thinking about module choice, final projects/dissertations, careers).

It can seem overwhelming after simply picking a degree because the subject or title seemed to fit with their interests, and getting through the core or ‘basic’ modules they are not so keen on is particularly hard. Some asked for clear “roadmaps” for completing a degree that would help them to choose modules, prepare for the next year and plan their studying well. This may make the first year seem less of a waste of time.

If students have nobody around them at home or school who understands a lot about modern university life, this makes it difficult to pick a university and course to suit their academic ability as well as interests – not everyone understands what a “good” university is apart from the famous names, and some ended up on a degree with an interesting course title but content that was not challenging enough and peers who did not want to work hard. Additionally, if the subject is a special interest for the student, some found they already knew all the first year material and that made it boring for them.

About 25% of respondents (Q1 and Q2 only) were interviewed for their university entry. They liked the interview as an opportunity to find out more about the course, and that they could tell the university more about themselves. Support has improved considerably when comparing those already out of university (no support) with those currently studying (56% reported 'enough support'). Around 40% took entrance exams. These are loved by some as they do not involve interviews, long application forms or group tasks and the questions can be interesting. However, those who did not have any support with preparing for the exam found it very difficult, some running out of time or being too anxious about what it would be like. The pressure to do well is hard to cope with.

8.1.2 Independence and Self-Advocacy

While many students describe worries about living with strangers in their first year of university, particularly those who are currently applying, students who do leave home appear to enjoy university more and be more independent than those who stayed with their parents. It also means they can live closer to the university, whereas commuting from home is stressful for some students. Working alongside study in order to rent a single apartment can affect how long it takes to complete a course.

Students say they wish they had self-awareness and self-advocacy skills to help them disclose their autism, understand themselves, ask for help and work better with others. “I feel I can never understand or explain properly what my needs are”. However, when given an opportunity like our surveys to talk about themselves, most are articulate about their problems and successes and clearly need the opportunity and support to share their needs and experiences in an appropriate way. Having to fight for appropriate support is difficult and tiring and the effort required is not well understood. This is the issue that nearly every student wanted to talk about, more than general social or sensory problems.

8.1.3 Managing Expectations

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

In some ways it is very different to school – less structure, having to manage their own time, not being told exactly what to do to get a good mark or how many hours they should study outside class, having to choose their own modules and not always getting their own way, having to live independently if they leave home. In others it is the same – most of their peers are not obsessed with their course and have other priorities, even now they have specialised in their favourite subject they still have to study things they already know or do not like, and they are no more likely to fit in socially. Some thought university would be a “magic bullet” where everything would be different and they could have a new start, and would interpret some of information they did receive about their university, their course etc in an unreasonable and delusional way.

Many students will spend a lot of time researching everything they do, to get this information and reduce anxiety. The information they usually receive about university and how it will really be after applying is too little and received too late. Not having good social relationships and too much being “unwritten rules” means they have to find out everything for themselves and this is exhausting. The positive side of this is most students really enjoy independent research in academic terms, and those who go on to higher research degrees love their work.

Those who had learned reflection skills found that thinking about past experiences and how they relate to current ones, their needs and likely outcomes was helpful to them. For some this ability to reflect and apply what they had learned came too late, after they finished their course.

Several participants found reading online about the experiences of other students, autistic and non-autistic, helped them to understand what was expected and what was likely to happen. Some chatted on forums with other autistic students. Others asked if they could have access to intelligent autistic role models – former students who have now graduated and are working in good jobs. However, not all autistic-to-autistic communication is welcome.

8.1.4 Diagnosis, disclosure and receiving support

The vast majority of students either do not disclose their autism to anyone at university, and most of the rest do not disclose it beyond disability services. Other students and teachers do not know. They find it very hard to tell people without either feeling like they are being judged or that they will change people’s opinion of them in a bad way. It is “embarrassing” to be autistic. This means they cannot access a lot of support or services and peers and teachers do not understand why they behave the way they do. Also many students were not diagnosed until partway through or after their time at university.

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

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

Most of those with university or state funded (not privately paid for) support workers do not have 24/7 access to them and therefore they need another way to cope in these situations. Sport/exercise, the internet, music and crafts are all helpful for coping with autism, according to our participants.

Asking for help at a time when they need help is difficult, because the thought of asking is stressful. Alternative, some students may only ask for help when they are in crisis and have already decided to leave. Also students find it difficult to express their needs well, or having their requests accepted, and can end up with support that is what the university usually gives students, such as software and support workers, instead of what they want, which may be peer support or academic changes.

Students wished they had met the disability team, academic staff and previous students before applying. The opportunity to experience a typical day (rather than one set up for visiting students) would have been

really helpful, as would the option of training on the paperwork and information on moving to a new city and living as a student.

Often disability support is set up at the beginning of the year (or later if it takes time to arrange or the student is late in applying) and then the student may have no more contact with anyone at the university who understands about their autism. This is a shame, as many students describe feeling isolated, an outsider, unable to take part in normal student life.

A good relationship with an understanding personal tutor (assigned in the UK to every student from their department), thesis/dissertation supervisor or another specific member of academic staff is really helpful, especially if they are open to regular contact via email.

There is a problem where the disability workers, who may or may not be helpful, are very separate from the academic staff. Just passing on information from one department to another is not successful. Disability support is not integrated into the academic department, where the student spends most of their time, nor into the social world of students. Support outside of university or from autism-specific organisations does not understand the university world or the subject. Social training or groups are separate from day to day interactions with course-mates.

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

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

8.1.5 The social environment

When asked about things they liked at university, answers relating to academic achievements are dominant. Students like that they are learning a lot (60%), they enjoy what they do (53%), and the marks and acknowledgement they receive (43%). A smaller proportion of students declare that they are happy with their social contacts and the support they receive (20-30%). This is mirrored in replies to a question about dislikes: Around 50% of autistic students feel they do not fit in, or do not have many friends, or feel they are made to do things they don't actually enjoy. Group work and other activities that are based on social interactions particularly stood out as an area of great dislike.

Most of our participants do not find social skills training (or similar initiatives) they have had very helpful, even though many have experienced it. More specific options, such as coaching and tutorials to get through entrance exams or reminders via social stories or support workers to adjust clothing, eat at regular intervals and so on, are valued more. Students would also like support, rather than training, to make friends with other students on their course and their flatmates. They may have learned how you are supposed to make friends or build relationships generally but applying what is learned in real situations with people who matter is not easy.

8.1.6 Reducing Anxiety

Our survey data showed that 44% of respondents have suffered from depression, and 42% have experienced anxiety at university. Students struggle to find quiet or suitable places on campus to escape when they are stressed or overloaded. They often end up hiding in the toilets or going home, though many value university libraries when they are not too busy, too noisy or too silent. They also do not always have a quiet place to live and struggle with sleep problems.

Specifically, survey respondents said they found these things particularly stressful:

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

Information is one of the main things that helps students with anxiety. When students do not know the marking criteria for an exam or assignment, they struggle. When they cannot find information about a situation, they struggle. If they do not know exactly how a course or module will go or modules they had researched are changed or removed, this causes problems. Most students wish they had more information about courses and modules before they started, including assessment methods, and wish they had known that the more specialist and interesting work would not take place until the final year of study.

8.1.7 Preventing Dropping Out

The students who dropped out shared some ideas for things that may have prevented this, and some of these people successfully returned to education:

- A diagnosis
- More financial support
- Able to change from full-time to part-time
- Flexibility over taking time out from the course or taking longer to complete
- Better self-awareness
- Better access to disability support (not enough staff, hard to contact, long waiting lists, need support to access the appointment for support)
- Academic staff who understood impact on learning as well as social difficulties
- Knowing earlier how a lack of social skills would impact on the ability to do a particular course/career that required liaison with lots of different people
- Reduced amount of group work (but it was accepted that if they had got to know other students better, it would have been less of a problem)
- Support to plan studies
- Advice on independent living

- Asking for help or talking to people instead of trying to manage alone
- Being able to tell people about problems without being aggressive or being seen to make excuses
- Lack of stigma for mental health conditions and autism
- Support that doesn't patronise autistic students or think they can't achieve as highly as everyone else
- Stopping trying to be perfectionist with life and work so things actually get finished
- Disclosing
- Finding a supportive member of academic staff who understands
- Looking more carefully at the assessment modes for modules
- Choosing a course more carefully – imagination can be limited at high school, considering only courses in areas already studied, and not how it might lead to a job or whether that sort of job would be suitable.

8.1.8 Country-specific paradigms

Students in the UK, Poland and the Netherlands generally seem to see the expectations of society and university as more of a barrier to them than their disability in itself, and they do not view problems as solely their fault. Whereas Spanish and some of the Finnish students (those who are not part of the autism/activist community) see themselves as the problem and speak more about medical style help (including psychologists, psychiatrists, rehabilitation workers) to make them 'better'.

This may reflect the popularity of the different models of disability – the social model and the medical model. The former group are more positive about their capabilities and less positive about the way universities are organised for the benefit of the mainstream student.

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

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

In the Netherlands and Finland, HE institutions typically offer autistic students counselling by a psychologist, study advisor with training in autism issues, or similar professional. Group sessions may be offered to support planning studies, managing anxiety, developing study skills, or other specific areas.

Other types of support, such as financial benefits or long-term support, often crucial to the student's successful progress, may be provided by health care or disability services outside the HE system. Complex rules and legislation can pose challenges to both students and their supporters.

The situation in Poland bears resemblance to these countries, but there are at this point very few autistic students declaring their diagnosis to HE institutions, and the development of specific provision is in early stages.

In Spain, the development of provision for autistic HE students has been driven by strong autism organisations and a number of innovative projects run by universities, especially in the area of supporting secondary education students and creating accessible entrance examination conditions.

At the national level, the range of services and adjustments is broad, but there is some variation depending on provincial administration.

8.2 Parent and Carer responses (Q4)

48 people responded to this survey questionnaire, 47 of which were parents. The gender balance of children/students was 44% female, 54% male and 2% 'other'. Participating parents were articulate in their responses and were happy to share their experiences in great detail.

8.2.1 Support

Respondents felt that universities generally do not have specialist autism units or personalised provision for students who cannot cope with a classroom full of other learners. 31% of respondents declared that their child did receive no support at all (although it is not known whether this was related to a lack of diagnosis or disclosure – in fact parents of students without diagnoses are upset by the fact that even if the university wants to support the student, they “cannot” provide this support without the official diagnosis). When comparing the various education stages, secondary education stands out as the stage with the most pervasive support (69% of autistic students) compared with 50% at primary school level and 29% at further education level.

Those who do receive support typically have adjustments to assessments and/or an additional tutor or support worker, although individual feedback suggests that few universities or individuals can finance a regular support worker, personal assistant or teaching assistant that can be with the student consistently for the whole of each working day. One parent said their child has a support worker at university who “translates” the language used into more concrete terms and simplifies questions for them.

Parents would welcome arrangements for a reduced or flexible timetable outside of normal part-time modes of study. There is a strong feeling that one size does not fit all for teaching – not just autistic spectrum versus mainstream, but also every learner is an individual and benefits from individualised provision rather than what is deemed suitable for autistic students or what has worked before for someone else.

Parents felt that a lot of transition work, as with support, comes too late. Preparation for going to university should happen before the school year that they apply for university, preferably the year before or earlier.

Respondents also reported that it can be difficult to get financial support for one's child: for study, for any kind of therapy, to cover the extra costs of living alone or commuting from home instead of living in university accommodation with others, to pursue any professional interests.

8.2.2 Adjustments

While a significant number of students receive no support or reasonable adjustments for their autism, an equally significant proportion receive a lot of support at school that would be difficult to mirror at university and parents do not mention weaning them off this support as part of transition planning. Other adjustments to requirements at school, like allowing autistic students to pass with a lower passing grade, are also unlikely to help in the transition to university or work.

Several parents ask for exams and assignments to be made easier or simpler for their child or state that this already happens at school or university. Interestingly, none of the students asked for or mentioned this.

Some parents said that at school or university exam and assignment questions were changed from open to closed ones, for the student with more contextual information included or shown to the

student before the exam. This may be acceptable in their situations, but in many universities across the world this would be considered unreasonable, as among the learning outcomes for the module and one of the transferable skills students are expected to learn is to be able to understand academic language and work out what is understood of them in an assignment or exam for themselves.

Some school-level provision can be replicated in HE, however, like extra time and a smaller room for exams, mentor, study buddy/peer mentor, academic skills support (which is often provided to all students), laptops in the classroom and in exams.

8.2.3 The role of the teacher or lecturer

Several parents think that school teachers should be responsible for teaching the children life skills such as cooking, time management, money management and travelling on public transport.

Teachers, on the other hand, think this responsibility lies with parents and support workers outside the school or college system.

It is probably unrealistic for either parents or students to meet every member of teaching staff with whom the student will interact (as one parent suggested), but as parents who have worked with autistic students beyond their own child have observed problems interacting with staff as well as other students, meeting the student's personal tutor or course director may be useful and some support for that first interaction could be even more helpful.

Teaching staff at university often say they have very little information about how autism affects the specific student in specific circumstances – they get no information at all (even if the student discloses) or general information about ASCs that could apply to anyone. Unsurprisingly, they are not happy to speak to parents on the student's behalf (in many countries this would be a breach of privacy and data protection laws). However, students are not always confident to talk to lecturers or later employers about how their condition affects them, as evidenced by responses to Q1-Q3. And with 90% of parents feeling that they need to advocate for their child in order to receive the support they need, this presents a problem.

8.2.4 Positive role models

It would be useful for parents and students to meet current autistic university students and recent graduates, as a role model for what success might look like and in order to discuss the benefits and challenges of that particular university for an autistic student.

Spanish parents feel concrete examples of situations are useful to help students recognise emotions and to understand they are not the only ones having these problems, without the stress of experiencing them for real. Perhaps combining this with the desire to know about successful autistic students may be productive – autistic peers could share common university situations and what was learned from the outcomes. Sharing real experiences involving the student or people they have met is perceived to be more useful than hypothetical or generic examples.

8.2.5 Strengths and weaknesses

Often other people only see the negatives of the autistic student and not their talents. Parents and carers in the UK and Spain in particular wish there was more support in choosing the right course and some sort of career guidance before university begins. Better understanding of both the strengths and challenges of the individual student, making no assumptions based on their autism or their IQ, is needed. This is possibly something that could be tackled at home as well as at school, which would be more empowering to the student: 25% of parents feel not very confident about their child's academic ability.

It is worrying that some parents already expect their child to be stressed, miserable and drop out. The students worry that nobody expects them to do well, and the literature says students do better when autistic students are encouraged to focus on the positive rather than their anxieties and difficulties, and yet their families think so negatively.

Students need to be more reflective and realistic about their strengths and weaknesses in relation to their interests and possible careers, and may benefit from tools to help them carry out a SWOT-type analysis (strengths, weaknesses, opportunities, threats).

8.2.6 Managing expectations

48% of parents anticipate their child to still live at home whilst attending university, citing family support, familiar surroundings and a certain oversight of study activities as the main reasons. For those that do more away, and early start should be considered. Several parents ask if this could happen. In the UK, international students have their own 'welcome week' at many universities before the other students arrive, to allow them to familiarise themselves with the city and campus and living there for real before it gets busy. Perhaps this could be extended to autistic students and other countries.

Parents also wish that students could contact their new flatmates ahead of time – this happens informally via Facebook groups and forums, but less socially confident students may not want to communicate semi-publicly like this.

Lack of information about what is really going to happen bothers both students and their families. Some parents have no experience of university, some have but it was so long ago and a lot has changed (some parents are aware it has changed, some don't show awareness of that).

It is difficult to manage excitement about university in such a way that makes it remain a positive force, rather than turning into anxiety.

8.3 Teachers and Mentors (Q5)

24 individuals responded to the survey, 14 of which were teachers and 10 of which worked in mentoring or other specialist support. The institutions they came from had on average 17% of their students diagnosed with autism, indicating that there were a number of specialist schools in the responses. 58% of students on the autism spectrum also present with ADD or ADHD – a surprisingly high number.

Respondents think the biggest issues for autistic students will be dealing with change, change management and communicating with teaching staff and peers. Other 'basic' difficulties include meeting deadlines and organisation skills, alongside the usual worries about socialising appropriately.

Teachers, like parents, worry about the lack of flexibility in assessment at university, which is necessary to maintaining both rigour and qualification quality. University assignments and exams will only accept certain types of responses and there is a fear that the "traditionally academic" approach will alienate those used to more leniency and "special arrangements" when meeting requirements. It is possible that subjects that reward more divergent thinking and different approaches to study may work better for some students.

As with other stakeholders, teachers worry about the autistic students' ability to interpret abstract language and complex questions. This is something that needs to be developed before they leave school and scaffolded during transition, as it is a key skill for university study. Students also need to learn to check whether or not they have understood what has really been said, or misinterpreted it.

Teachers feel that autistic students will excel at

- working hard,
- doing as they are told (directly, unambiguously),
- researching topics (especially on the internet), and
- using the library to work on special interest subjects.

Small tutorials on topics related to the student's special academic interests may boost confidence due to their knowledge and comfort with the topic. This may be hard to fit into a typical first year of core courses. Autistic students are not always aware of their own potential, because so much focus is put on their difficulties. Teachers recognise that there are positives as well as negatives to autism and wish this was better understood by teaching colleagues, families and students themselves.

8.3.1 Change of culture

Some things students may have been able to avoid at school, like working with others or working with people they would not choose to work with, may be unavoidable at university.

If a student needs to ask a question to clarify something, they need to be able to do this in front of the whole class. It is not appropriate to keep approaching teaching staff after a lecture or send emails, and asking in public benefits other people with the same query. Teachers find that autistic students are also less likely to ask questions, like directions around campus, of their peers.

Students are used to personal attention at school – everyone knows them, is aware of what they are doing during a lesson, they may well be noticed if they are upset and they receive one to one interest in their work. This is rare to non-existent at university.

Several teachers believe that autistic students will find it difficult to adjust to the way that university teaching is delivered mostly verbally in big lectures, and the rest of the learning is via independent study. Some school students find lectures and group discussions pointless, as nothing is directly produced from the session. Teachers do not however mention preparing students for this change.

The difference between 'school life' and the 'university world' is likely to be a problem. Universities are much bigger and more impersonal than schools, and sensory overload is more of an issue.

Students are used to knowing their support network at school very well and knowing exactly when those people will be available (usually all the time or in the same shifts throughout the school week). There are concerns that this is not really possible at university.

8.3.2 Independence and self-management

Independent working is a concern, particularly managing a schedule where not all the study and rest periods required are in the student's timetable. The pace of work may also be an issue.

Students are not encouraged to become self-reliant in managing their time and work at school. They depend on parents, teachers, the regularity of the school timetable and for some, support workers. 75% of teachers/mentors report that autistic pupils are regularly accompanied by their parents when meetings about their autism-related needs take place. This may be due to the age of the pupils and comparative data for non-autistic pupils is not available, but the fact that a significant proportion of pupils attend these meetings on their own shows that it is possible. Teachers feel that parents of autistic students are too protective and this can hold back students' independence at a time when they need to develop autonomy.

Students who do not leave home may find their lives to be more comfortable and the routine could improve academic performance, but they may struggle to develop socially and could miss out on

social, academic and employment opportunities. Developing real independence, which is a key issue highlighted by teachers, would be more difficult. Maintaining the usual routine at home limits the capacity for engaging in new activities and taking a full part in student life and really getting to grips with change and adaptation. This makes later transitions to work and adult life harder.

8.3.3 Living away from home

Many teachers and mentors consider living in student accommodation as an unpleasant experience for the student. This is against 79% of respondents thinking that their autistic pupils may well move away from home when going to university. Moving away could cause anxiety due to losing support networks, but living at a university close to home with regular visits to/from home could be a good compromise and would result in better skill development, independence and being treated 'like an adult'. Needing to make decisions alone is an important skill that can be safely learned at university and the student is more likely to be able to get a job. It may be more stressful for the student initially to move away, but once they are in a new routine it will make things easier in the long term.

On the positive side, without parental pressure to study at a university near home, the student can choose subjects and modules they really want to study instead of trying to please their family or being restricted to the subjects offered at their nearest university. This could increase motivation and self-esteem.

Spanish respondents are more likely to think that staying at home or moving away has no effect on the student. However, the majority view by teachers is that it does cause problems to stay at home, and the lack of support for transition from school to independent living and for inclusion at university is the real issue with moving away in the face of the benefits of doing so. Contact between the school and relevant contacts (disability services, housing, academic department) at the university can be helpful.

8.3.4 Practical considerations

Physically getting lost on campus is a big issue for autistic students; both in terms of anxiety from thinking about it and the reality of it happening, and campus maps are not particularly helpful in this regard. If the student is not part of a larger group of peers, they have nobody to follow, and not everyone is going to the same place anyway.

There is some concern about students' ability to take notes – either to do it at all or take notes that are actually useful (it is neither possible nor helpful to write everything down). Support from an external note taker is becoming less available at university, so the student needs these skills. They may not realise they have a problem, so will not find out that the university offers classes in academic skills like effective note taking.

Some teachers think students will be shocked by the amount of time they are expected to spend learning, because it is not just about the contact hours on the timetable. Others think some students will need to be reminded to take breaks, eat and socialise as they expect to be working all the time.

Gaps between classes (too short to go 'home') may be difficult for those who do not make acquaintances easily. Spending those periods alone, even if the break is welcome, may accentuate the differences between them and peers.

8.3.5 Social issues

Autistic students imitating other students to fit in may have adverse effects – they smile and nod when asked if they are OK with the work, but if asked a question it becomes clear that they have not actually understood. As they may not get on well with their peers, they cannot casually check what

the lecturer meant with friends later as a neurotypical student pretending to have understood may do.

Students need to be both more inclined to talk about their difficulties and to have both the self-knowledge and skills to do so in a calm, considered manner that is not rude or emotional. Their peers, disability staff and teaching staff find it difficult to help them otherwise – they too cannot read minds.

Students may vocalise irritation with lecturers or other students being late. This is inappropriate. Teachers perceive autistic students as often being “moody” or rude before the lesson even starts, and worry they will take this behaviour on to university where it will be even less well tolerated.

Support that is available at university, e.g. social groups or mentors, is not differentiated or targeted enough to fit the needs and interests of all autistic students and meetings often take place too infrequently.

8.3.6 Transition support

The support for transition offered by schools varies widely, by school and not just by country. Relationships with local universities can lead to visits and tours. Careers advisors at school can offer support for choosing courses and universities, but their knowledge of specific subjects and departments at different universities may not go beyond the prospectus. Some schools offer life skills support, and training on dealing with cyber safety. Some do not.

Existing social skills training and counselling/therapy sessions may include exploring transition-related situations or may not. Support for transition may be provided by careers advisers, school counsellors, teaching assistants or embedded within subject-specific lessons by the teacher. One school provides assistance to attend local university open days and ensures the student has a one to one interview. Another organises visits to a variety of universities across the country, which is probably less limiting for the students’ aspirations. Some support is specific to autistic students; other support is core to all students and is delivered with understanding of autism. No preparation for the way students are expected to study at university is available before they start.

Universities often don’t respond to requests from schools for named contacts that will meet with students before the course and that can be relied on consistently once the course starts.

Teachers suggested that autistic students would benefit from the following support when they got to university:

- A consistent staff contact (e.g. personal tutor) who understands the subject the student is studying and with whom the student has a strong relationship
- Meeting autistic students who are doing well and/or hearing about their experiences at that specific university
- Better campus mapping/directions, as being able to read the existing maps can be a problem
- Early arrival at university, before the other students start
- Writing their own student profile and giving it personally to teaching staff so that specific problems and potential solutions can be understood
- More cooperation between universities across the country and secondary schools – not just the local universities
- Teaching assistant or mentor who stays with the student
- Autism-specific training for lecturers/tutors
- Families who are not over-protective
- Specific preparation from the department before they start for their specific course

- Better understanding of their own condition, for themselves and to explain to others
- Learning how to interpret abstract language
- Tutors encouraged to monitor the student's attendance and progress in every class
- More individualised support from mentors – currently too generic

8.3.7 Student expectations

Difficulties experienced at school such as lack of understanding of autism from teachers (a key issue mentioned by most respondents), lack of time to give full support even if the will is there and the unpredictability of the environment are likely to be repeated at university but on a bigger scale and are hard to resolve. Getting a new start does not mean these problems go away – students need to be aware of this.

Rigidity of thinking combined with pressure from parents means that autistic students can decide on a course or university too quickly, before they have properly considered all the options. They also rarely think about taking a break before university to develop the skills and maturity they are lacking or make a more informed decision – it's now or never, university or nothing. Vocational and work-based learning options are not even considered by many students and their families.

Autistic students are good at pretending to be OK, and you only find out they are not when they are in crisis or meltdown. They do not ask for help until it is too late, either to understand the work or to cope with what is happening to them. Mental health problems make students even more difficult to communicate with, and getting genuine feedback even from stable students can require a very firm approach.

8.3.8 Autism awareness

Only 26% of the respondents consider themselves 'specialists' in autism support, despite the high percentage of autistic students in the institutions being questioned. 80% feel that more training is needed. On the other hand, 58% said that staff they work with recently had autism-specific training.

Teachers repeatedly state the need for better communication between students, the teachers, families, school administration and autism organisations – about autism as a whole but also for individual students and their specific needs. This is also needed at university level. The students' peers need to understand autism better, and when they do this is often the best form of support for an autistic student. Some schools run activities for non-autistic students to raise awareness and understanding of the characteristics of autism.

8.4 Higher Education Institutions (Q6)

25 respondents completed this questionnaire, covering all partner countries and a wide range of roles:

- lecturers in different subject areas,
- psychologists specialising in supporting students,
- people in disability support and student services roles at various levels,
- subject-specific study advisors, and
- specialist autism support tutors.

Some work solely with disabled students, some have an autism specialism and others have a wider remit. All support students on the autistic spectrum as part of their role.

8.4.1 Perceived impact of impairments

Students on the autistic spectrum are perceived as having the same range of intelligence as other autistic students, but with more interest in their topic of study. While skills that cross the life/study

barrier such as time management, social interaction and executive function are problematic, most HE staff also report problems with academic skills such as planning work, analysing and synthesising material and writing essays within the word limit that address all the relevant areas well. Lecturers also find it frustrating that autistic students struggle to focus in lectures and in group work and feel they should have better guidance when choosing subjects and modes of study. There can be a conflict between the support needed or previously experienced at school and the requirement to become a fully independent learner at university.

Responses to the other surveys show that many autistic students have co-morbid mental, neurological and physical conditions, and this is confirmed by HE institutions too with 64% of autistic students affected by anxiety, 44% by depression, and 40% by ADD/ADHD. Respondents also specifically notes the physical difficulties faced by some autistic students, perhaps particularly those with dyspraxia and motor disabilities. Fine and gross motor control can be a problem, which can affect confidence, performance in e.g. the chemistry lab and the precision required by some technology. Conversely, working with new technologies and the confidence some autistic students have in using these can make it easier for autistic students to fit in with the majority group.

8.4.2 Screening and assessment

44% of responding universities screen for specific learning difficulties (SpLDs) such as autism, ADHD and dyslexia. However, the availability of this screening and means used to do this differ greatly and most universities still rely on disclosure from the student, accompanied by medical evidence of a diagnosis. Some of these assessments/screenings clearly only take place after the student has started the process of accessing disability support or is regularly meeting with disability staff.

Students who do not yet have a diagnosis (according to the National Autistic Society, over 60% of people with autism were not diagnosed until adulthood) or who do not declare their condition are still unlikely to be picked up by staff as potentially being autistic or eligible for support.

Several of the Spanish respondents were reliant on information and signposting about individual students from Autismo Burgos, one of the Autism&Uni project partners. Students in that area without a diagnosis, or with a diagnosis but not accessing support from AB, may be less well supported.

8.4.3 Self-advocacy

A high percentage of institutions (68%) report that autistic students usually attend support meetings on their own, i.e. without a family member or other supporting person. This is in contrast to 75% of pupils attending meetings with their parents when at secondary school level.

8.4.4 Diagnosis and Support

Universities are willing to provide students with printed and face-to-face information about autism diagnosis and autism support. Nearly half of the respondents use third-party agencies to deal with diagnosis, which is not unexpected as in many countries diagnosis has to be carried out by a medical professional.

Support for autistic students often focuses on autism-specific issues, but some universities provide academic skills classes and resources for all students and a joined-up approach would direct autistic students to these as standard instead of addressing these issues with their mentors or disability support workers, or leaving the student to recognise they have these needs.

In some cases (mostly Finnish universities) disability services meet the students only once, to assess their needs, at the beginning of studies (or when they have had a diagnosis, if that happens after university entry). These respondents declared that an ongoing relationship between student and

disability support is not possible unless the student specifically asks for it, on a case by case basis. Most universities however offer mentors, buddy programmes, orientation days and regular meetings with a named support person, not just in the initial weeks but throughout someone's study.

The support services and adjustments that appear to be most effective are:

- Regular arranged meetings with the student, not just on demand
- Consistent personalised 1-1 support with the same, trained person
- Help with timetable planning and priority listing
- Maintain good links between support and teaching staff
- Positive reinforcement and acknowledgement of student achievements
- Allow alternative ways of assessment by default (without having to arrange it)
- Autism awareness sessions for teaching staff, and in some cases for fellow students too

The main challenges identified by universities are:

- Time constraints
- The variability of the characteristics between students and meeting the needs of individuals (rather than offering one-size-fits-all support programmes)
- Students not turning up to meetings or classes
- A disconnect between disability support and academics
- Assessing needs and challenges before a course has even started
- Lack of autism awareness training in support staff

8.4.5 Reasonable adjustments

The most common adjustment autistic students receive from their university is changes to exams (84%) which may involve more time to complete the exam or changes to the language used in the exam. This is followed by changes to teaching materials (40%) and changes to coursework assignments (also 40%). 36% receive help from a support worker within the HE context, and 32% from a tutor outside of university.

Most students can find out about the adjustments available before they arrive or during the first few weeks of the course, although this may be dependent on whether they have declared their condition or are otherwise in reach of disability services. 56% of respondents state that students only get the relevant information when they specifically ask for it, and a more anticipatory and pro-active approach by the universities may avoid delay in support being arranged.

However, as mentioned above universities can generally not provide full support including reasonable adjustments if the student does not already have a diagnosis. Some universities provide scaled down specialised support e.g. one to one meetings, or support that is available to any student, whether autistic or not.

8.5 Autism Organisations and Professionals (Q7)