

SUPPORTING STUDENTS ON THE AUTISM SPECTRUM THROUGHOUT THEIR UNIVERSITY STUDIES

María Merino, Miguel Lancho, Christian García

{psicologia, miguellancho, aliso}@autismoburgos.org
Autismo Burgos (SPAIN)

Abstract

Students with Autism Spectrum Disorders (ASD) often find it difficult to deal with changes. They need specific support to manage transitions, especially those which involve a variety of demands in different areas of life. The transition from high school to university and higher education is an example of such a period in a young person's life, involving social, personal and academic demands.

In the Autism&Uni project, we have collected data from students with ASD, their families and carers, as well as specialists and professionals in higher education institutions. This data has been analysed to identify supports that could help students with ASD to achieve academic and social goals, and to collect examples of good practice from the countries involved in the project.

The results emphasise a number of critical periods. Prior to the transition, vocational guidance is crucial. The students may have difficulty making realistic choices that are based on their skills rather than just interests. Acquisition of independent living skills is an important goal that can affect the choice of courses. For equality in terms of access to higher education, some students with ASD also need specific adaptations in the exam situation to avoid sensory overload and stress-induced loss of concentration.

First-year students identified needs regard specific academic support and assistance with daily living skills. They need to establish structure, find their way to various locations and learn to manage their timetables. They face the tasks of disclosing their diagnosis, engaging socially with other students, and handling study-related paperwork.

In the later stages of their studies, typical support needs involve exam situations, dealing with anxiety, developing social support networks, and accessing grants and other forms of financial support.

Keywords: autism spectrum, higher education, transition, support

1 INTRODUCTION

Probably the first descriptions of people with cognitive features resembling autism and Asperger syndrome were written by Grunya Efimovna Sukhareva in 1925, describing boys with normal to high intelligence [1]. Kanner's description in the 1940s reflected difficulties in communication and social interaction, especially in understanding ambiguous situations or emotional components [2]. Like Kanner, Asperger noted that the children he described did not desire isolation, but difficulties arose from their failure to understand and adjust to social situations. He described educational aspects of vulnerability to ridicule and harassment, details on mental rigidity, difficulties in establishing friendships, finding pleasure in repetition, excessive attachment to objects, dislike for novelty, clumsiness, stereotypes, poor posture, difficulty with fine motor skills, and certain difficulties related to academic performance, such as trouble following long explanations. Asperger also described positive aspects such as good memory for detail, vocabulary, ability to focus on specific topics, original thinking, and a growing awareness of their own differences as they reached adolescence [3].

Students with autism have different special needs that show variability depending on the context of the person and of the characteristics of the disorder. For a long time, students with autism have gone unnoticed or been misunderstood, partly because the disorder has been included in the diagnostic manuals only recently. Also, it can be difficult to know and recognize the differences and the barriers to learning that may affect such a student; his "mental blindness" [4] is complex and sometimes not evident to education professionals. For example, a student with autism who enrolls in college may struggle with transitioning from high school to a less structured and more complex college environment [5]. Highly specialized knowledge is required to understand the student and to provide appropriate intervention in the education system.

This article explores the barriers to learning faced by students with Autism Spectrum Disorders (ASD) in higher education. The issues are illustrated by selected findings from seven systematic surveys that were undertaken on the topic, using questionnaires and forms with open-ended questions to prompt participants to tell their personal stories.

Different questionnaires were designed for different target groups; individuals with autism, parents and carers, professionals working in autism organizations, professionals involved in accessibility and guidance for disabled students and within educational institutions.

Listening to the experiences of students with ASD has the advantage of letting individuals express their 'lived experience' of being a student in Higher Education. This approach highlights the social and sensory barriers that the students encounter.

The findings in our research show the variety of experiences and the need for help which can be adjusted flexibly. Students, families and carers described the learning needs for students with ASD in HE, along with support strategies that showed varying levels of success.

2 INTERNATIONAL FRAMEWORK OF SUPPORT FOR PEOPLE WITH DISABILITIES

There are several organizations that encourage an international framework for the rights of people with special needs. Among these are the United Nations (UN) and the United Nations Educational, Scientific and Cultural Organization (UNESCO).

In 1976, the UN created the International Bill of Human Rights for the development of legislative framework to promote equal opportunities. This led to the creation of the International Convention on the Rights of Persons with Disabilities in 2006.

The set of documents that support the International Bill of Human Rights are: the Universal Declaration of Human Rights (1948), the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, and the Optional Protocol International Covenant on Civil and Political Rights (the latter in 1976).

In the Universal Declaration of Human Rights (1948), the right to education of all persons (Art.26.1) was included, with the statement that "*education shall be directed to the full development of the human personality and strengthening of respect for human rights and fundamental freedoms...*" (Art.26.2), and with the assertion that parents have a right to choose the kind of education that will be given to their children (Art.26.3). These two rights were also bolstered by the International Covenant on Economic Rights (1976).

Art. 26 of the International Covenant on Civil and Political Rights includes the following "*... the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination...*".

In 1990, as part of the "World Conference on Education for All: meeting basic learning needs" two important documents were approved: "The World Declaration on Education for All" and "Framework for action to meet the Learning basic needs". The former stated, in Art.3: "*the basic learning needs of the disabled demand special attention. Action is needed to ensure these people, in their various categories will have equal access to education as an integral part of the educational system*".

In 1994 the UNESCO World Conference on "Special Educational Needs" proposed a global framework of attention to these students, which was reflected in the "Salamanca Statement on Special Needs Education: Access and Quality".

The European Parliament adopted on May 9 1996, in the form of declaration, the Charter of the Rights of Persons with Autism. It states that "*people with autism are entitled to accessible and appropriate education for all*".

The International Convention on the Rights of Persons with Disabilities, Article 24, stipulates that "*states must ensure the right of persons with disabilities to education, ensuring an inclusive education system at all levels and throughout the life of the person, qualified by education professionals, trained in proper techniques and to support people with disabilities educational materials, providing at all times individualized supports*".

In the course of the Autism&Uni project we saw evidence of how each country has different laws to support and ensure the development of these rights.

In the UK, the Equality Act (2010) makes it illegal for a school or other education provider to treat disabled students unfavourably. This includes:

- Direct discrimination - e.g. refusing admission to a student because of disability
- Indirect discrimination - e.g. only providing application forms in one format that may not be accessible
- Discrimination arising from a disability - e.g. a disabled pupil is prevented from going outside at break time because it takes too long to get there
- Harassment - e.g. a teacher shouts at a disabled student for not paying attention when the student's disability stops them from concentrating
- Victimization – e.g. suspending a disabled student because they've complained about harassment

Through the Equality Act Guidance some reasonable adjustments are proposed:

- An education provider has a duty to make 'reasonable adjustments' to make sure disabled students are not discriminated against. These changes could include:
- Providing extra support and aid (such as specialized teachers or equipment)
- All universities and higher education colleges should have a person in charge of disability issues that you can talk to about the support they offer.

In Finland there are basic rights to promote equality:

- The Constitution of Finland (Suomen Perustuslaki 731/1999), Chapter 2,
 - Declares that everyone is equal before the law, irrespective of illness, disability or other such factors
 - States the right to sufficient social services, including disability services, at a level that enables all to participate in society as its full and equal members
 - Requires that state authorities must act to ensure that these rights are realized
- The law on equal treatment (Yhdentvertaisuuslaki 21/2004)
 - Requires that all HE institutions provide reasonable adjustments
 - Promotes and ensures equality, provides enhanced protection before the law in case of discrimination on the basis of disability or illness (also gender, ethnicity etc.)
 - Promotes equality, an employer or provider of education must make reasonable adjustments, if necessary, to ensure that work or education is made accessible to a disabled person, and that they are able to perform their work or studies and to proceed in their career. In considering what is reasonable, the cost and chances of receiving funding to cover the cost is taken into account.

In Poland, the Ministry of Science and Higher Education allocates funds to universities for the purpose of providing support for disabled students. The amount of money depends on the number of disabled students declared by the universities. Disabled students can also apply for a social stipend/grant.

In every Polish HE institution there is an Office for People with Disabilities. Every student who provides diagnostic statement (certificate of disability) receives support and help adjusted to their specific needs (e.g. connected with learning difficulties or difficulties in mobility)

Spain has recently approved the creation of a National Strategic Plan for people with autism.

- The Law of the General Educational System (LOGSE, 1990) represents specific legislation to ensure that the education system has the necessary resources and that these are allocated correctly. The aim is that students with special educational needs can achieve, within the system, overall objectives for all students through the necessary curricular adaptations and personal resources available, as well as suitable materials. The need for specialized professionals is also recognized.
- The Law on Education, 2/2006, (better known as LOE), emphasizes "... Equity, ensuring equal opportunities, educational inclusion and non-discrimination, and acting as a means of diminishing personal, cultural, economic and social inequalities, with special attention to those arising from disability".
- 'Equity in Education' states that "teacher education authorities will have corresponding opportunities for specialization and qualified professionals, as well as media and materials needed for proper attention to these students. It is the task of the education authorities to provide schools with the necessary resources to properly care for these students".

3 SUPPORT FOR STUDENTS WITH ASD: AUTISM&UNI FINDINGS

3.1 Needs

The experiences of ASD students are varied. Some encounter significant barriers, others are not aware of any; some find the support they receive highly praiseworthy, others find it does not meet their needs.

The most common problems related by the students with ASD in higher education are: lack of friends, difficulties in dealing with group work, lack of motivation concerning certain activities or subjects, feelings of isolation or of 'not fitting in', difficulties in managing changes in timetables and schedules, difficulties in planning and organizing study-related tasks, difficulties in managing stress and anxiety, problems with exam situations, and lack of specific support.

The actual supports that the students received are: teaching assistants, mentors, external tutors, changes in exam arrangements, help to plan schedules for study and free time, support from disability funds, help to deal with deadlines, and permission to audio record lectures,

Supports applied at the college entry stage included getting to know the university facilities before the semester started, and information about the first year of college. Sometimes aid was also provided to manage paperwork and to meet support services for the disabled.

With regard to needs and supports in exams, we found a significant number of students with ASD who feel that they do not have enough time to answer questions at exams. They felt anxious about their own abilities, suffered from a lack of confidence, and missed the more structured and predictable situations they had experienced at school. Some had specific difficulties that had to do with sensory overload in the exam situation.

3.2 Support

The process of entering Higher Education presents in itself a whole set of new requirements for people with autism. For them – as for many other students – it represents the necessity of dealing with change. In many cases, it involves not only the beginning of a new stage in their education, but also a change of residence, learning to live alone or to commute to the HEI, as well as changes involving study partners, environments, routes, schedules and customs.

In fact, it is a feature of university activity that change is always present: change from one classroom to another, different study partners depending on the subjects, different methodologies, different seats, activities both inside and outside the classroom, as well as some inescapable social demands: with group work, schedules and course plans that often mean having to choose between one or the other activity. All this calls for demonstration of a broad range of self-regulation skills and time management which, as we know, are precisely those areas where people with autism need particular support.

In general, the support offered in most universities is managed by care services that cater for a diverse range of students with some form of disability. Usually, the support consists of interventions such as: changes or adaptations to the curriculum, exemption from payment of fees or specific support scholarships, procedures to support the start of the first course, Internet and electronic media facilities to improve accessibility, adapted materials, guidelines and specific suggestions for teachers, specific volunteer programs in academic support activities or extracurricular activities, counseling and employment support, and specific actions to promote employability.

There is a shortage of literature concerning best practice and the experiences of people with autism in HE. In some of the Autism&Uni partner countries, literature could be found that had served to support the educational community locally.

Many of these students feel that they benefit from having the diagnosis and communicating about their needs, such as the difficulty of dealing with complex schedules, constantly changing classes and teachers, or changes in announced locations. Being away from family adds to the complexity of the situation. Some have had negative experiences involving practical assignments, or with participating in group work. Many consider college materials more motivating than school, despite the fact that there are types of subject matter and styles of communication among teaching staff that may be difficult to understand.

Most of the participants agree that there is a need to develop specific support for students with ASD. The support should cover not only the academic context, but also other areas of daily life in order to optimize the adaptation and performance of the students during their university years. Before they start their courses, transition stage counselling is crucial. It is essential to provide assistance with the application process, explaining how to fill in the application form, what grants the student should apply

for, specifying what documents must be attached and what kind of courses and subjects are most suitable for them, providing effective information on services and resources so they can choose a degree.

However, it is also necessary to provide advice to solve problems outside the academic context during this time, for example by offering specific action plans to find accommodation. This can contribute to lowering the student's stress level before the courses start. The student may benefit from having someone explain the benefits and disadvantages of living in halls of residence, or giving them a list of places with different services or, if they prefer, helping them find private rented accommodation.

Also, it can be useful to make lists of belongings to bring when moving, telephone numbers and solutions in case of electrical appliance breakdowns, information about how to open a bank account, and other problems of everyday life. Students moving to another city should be put in contact with professionals specialized in autism who can be contacted at the new location.

Within the HEI context, the disability services should be closely involved in the lives of students with ASD, working as translators when communication problems arise, interceding with academic staff on the student's behalf, raising awareness and explaining the student's needs, challenges and strengths. Disability service staff can train other HE staff in inclusive practice, taking into account the diversity within the spectrum, and providing specific guidelines to enhance the students' performance.

Some of these guidelines might include curricular adaptations which target specific difficulties and unique learning styles. These can be related to methodology (e.g. the use of visual cues), objectives or forms of assessment (e.g. formulating clear and concise questions), but they may also refer to other kinds of adaptations such as setting up groups in a particular way and allocating the different tasks within these groups, or anticipating possible changes in the schedule or exams dates, offering flexible deadlines, providing explicit rather than 'unwritten' or implied information, providing the option of not attending long lectures or attending them online, using ITC environments in class, avoiding noisy rooms, or to giving alternative solutions to specific problems (e.g. the option of using a computer program instead of using laboratory tools if the student has motor function deficits or olfactory sensitivity). All these measures must be adjusted to the specific needs of the student, applying the support at a level of intensity appropriate for each situation.

Last but not least, other types of support that find a balance between social and academic life can be provided, for example peer mentoring or creating a special social groups for students on the autism spectrum. In such groups, the students can discuss their difficulties and share solutions to common problems.

3.2.1 Academic support

- Curricular adaptations to respond to possible difficulties and unique learning styles (in the methodology, objectives, evaluation forms ...).
- Peer mentoring: natural supports provided by peers.
- Adjusting the intensity of support to individual needs.
- Strengthening the role of educational support to cover areas outside academic support.
- Involving specialists in ASD in vocational guidance processes.
- University disability services acting as guides and interpreters to navigate students through specific issues with their faculties.
- Training academic staff in inclusive practice.
- Improving scheduling.
- Providing more explicit information, rather than unwritten or implied.
- Offering the option of not attending/ leaving large lectures without penalty, and offering access to recordings instead.
- Providing successful autistic role models.
- Thinking of accessibility in terms of sensory issues, tendency to "overload".
- Taking into account individual differences within the spectrum
- Providing visual cues and ICT environments to facilitate group work, exams and learning in general.

3.2.2 Improving accessibility through the curriculum

- Adaptation of exams (specific questions, avoiding double negatives, providing opportunities to practice taking the exam).
- Offering extra time at exams.

- Clarifying the available time and space by using visual cues.
- Assistance with note-taking.
- Providing visual supports (e.g. show an arrow to signal when the student should turn the page to proceed with the exam, use coloured cards to indicate the remaining time).
- Training students to use explicit self-instructions to steer their own actions.
- Coordinating the student's interactions with the environment by using digital platforms, meeting agendas.
- Training teachers on the challenges and skills of students with ASD.
- Providing support with understanding materials with social content or figurative expressions.
- Providing support to differentiate and define the most relevant aspects of subject matter.

3.2.3 *Support for daily life skills*

- Developing specific action plans for finding accommodation.
- Transition stage counselling: where to apply, what kind of courses to start, how to organise life in general.
- Environment and informal support: informal networking, students passing information to one another, learning to negotiate the system piece by piece while receiving advice and encouragement from peers both locally and internationally.

3.2.4 *Social support*

- Awareness and availability of autism related information.
- Effective information & advice on services.
- Special social group for students on the spectrum.

4 DISCUSSION

Laws, grants and scholarships, disability support, and autism policies are all different in the countries covered by this project. The ability to ensure equal opportunities for students with autism depends directly on the development of appropriate policies in each country.

Autism spectrum disorders require specific interventions and individual plans, delivered by experts in autism who should also be familiar with the HE environment.

Although there appear to be many university students with ASD, 70% of them finish college with very little success entering the labor market. Even fewer find employment within the field in which they hold their university degree.

In most people's lives, higher education represents a stage of expansion and social and personal development. For people with ASD, with expectations much like those of their peers, it can be a time of frustration because their social difficulties prevent them from establishing relationships with others.

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