

Consultation to the National Strategy for Higher Education

Submission on behalf of Aspire - The Asperger Syndrome Association of Ireland

Dear Mr. Cunningham,

Thank you for this opportunity to make a submission for the first stage of the Consultation on the National Strategy for Higher Education. The following report will highlight the three most significant changes we would wish to see made to Irish higher education and any barriers or obstacles we can identify towards the achievement of those objectives.

Introduction to Aspire and AS/HFA

Aspire - The Asperger Syndrome Association of Ireland was established by a group of parents in 1995 to provide support for those with the syndrome and their families, and to encourage and undertake research into the condition. Over the years the Association has developed support, educational and training services for people affected by the syndrome and their families.

Asperger Syndrome is a form of high functioning autism and people with this syndrome can experience great difficulties with communication, social interaction and flexible thinking. They can often develop obsessive, repetitive routines and are prone to clumsiness and also can suffer from bullying in schools and the workplace.

In many cases, these difficulties experienced by a person with AS/HFA can manifest themselves in later life in the form of high levels of anxiety, stress and depression. This greatly affects their chances of living independently, participating in higher education and employment. Most people affected by this condition are marginalised to the fringes of society. In order for people to integrate into mainstream life they need ongoing support and assistance.

Although a detailed study in the prevalence of this syndrome has yet to be completed, prevalence estimates indicate that, as an initial target, provision be made for services for at least 36 per 10,000 with AS/HFA (The Report of the Task Force on Autism – Dept. of Education and Science, Section 17.2, October 2001)

Although people with AS/HFA may present themselves to being very intelligent they social deficits and poor understanding of people means that they have major difficulties in coping with the world.

The authorities who decide on entitlement to disability services are sometimes unaware of the extent and significance of the disabilities involved in AS/HFA. Proficient verbal expression skills, overall IQ within the normal or above normal range, and a solitary lifestyle often mask outstanding deficiencies observed primarily in novel or otherwise socially demanding situations, thus decreasing other people's perception of their very salient needs for supportive intervention (Klin and Volkmar, 2000. p. 342).

1) The Establishment of Support Structures in Third Level Education

Although services for people with disabilities at third level have improved in recent years, there remains a long way to go before the types of comprehensive support required by people with AS/HFA are in place within the tertiary sector.

Intellectual ability, a tendency toward routine, observation of rules, and the focus of narrow interests are among the potentially positive factors for academic success and employability (The Report of the Task Force on Autism – Dept. of Education and Science, Section 10.7.9, October 2001)

Students with AS/HFA typically experience higher levels of stress and anxiety compared to their peers within the higher level environment. The causes of these stress levels can also be different when compared to other students, such as changes to the timetable or alternative seating arrangements within a lecture hall. Life outside of lectures and tutorials can also be challenging for students with AS/HFA.

Typically, students with AS/HFA can experience the following problems:

- Difficulty with examinations and group project work
- Difficulty with time management
- Experiencing difficulties in group situations which may affect attendance at lectures and tutorials as well as involvement in college societies
- Having difficulty in requesting information
- Not knowing what is expected of them in course work
- Difficulty working out study techniques to suit individual strengths and weaknesses
- Problems communicating with other students or staff
- Putting things off, finding it difficult to start essays and projects
- Feeling overwhelmed by the stress of college life
- Difficulty managing the effects of emotional stress and physical fatigue

- Feeling isolated in college which can affect relationships and academic performance
- Difficulty developing and maintaining a healthy and balanced lifestyle while at college

To prevent these from taking place, comprehensive support structures need to be established across all higher education institutions. These programs need to be designed to:

- 1) Assist students with AS/HFA to recognize and make use of their existing academic abilities.
- 2) Aid in the development of new abilities and to improve their social and coping strategies
- 3) Promote progress toward a higher level of independent functioning

Although most third level institutions now have their own Disability Support Service, there needs to be a more targeted system of supports available for students on the autistic spectrum. These would include: individual counselling sessions with these students, advocacy services, therapy sessions and student mentoring services. For students with AS/HFA, a student mentoring program would be extra advantageous as the mentor could offer support in a wide range of areas including: assisting the student to review their progress and plan ahead, managing deadlines, facilitating the student's access to University facilities and services (library, careers, leisure facilities, etc) and critically, encouraging the student to improve confidence and achieve independence and decrease their isolation.

Although some higher education institutions offer services similar to these (i.e. the Unilink Support services as offered by Trinity College Dublin), access to such services as outlined above needs to be made available at all third level colleges.

Reasonable accommodations need to be implemented for a person with AS/HFA within the higher level environment. Examination conditions can be adjusted to provide students with an environment where they feel most comfortable (i.e. extra time, strategies to overcome stress, use of a computer/scribe etc). Also, a certain amount of flexibility should be made available regarding the number of years needed to complete a course, with a possibility for a student to take time out if under emotional stress/pressure and rejoin at a later date.

2) Awareness Development of AS/HFA among staff of post leaving certificate, further/adult and higher education institutions

All staff working within the higher education environment need to be made fully aware of the syndrome and its characteristics. According to Task Force on Autism Report, misunderstandings, which arise because of social and communication impairments, are regularly exacerbated by lack of awareness among staff of mainstream education/training institutes.

There is an urgent need for the following measures to be implemented across the range of mainstream educational and vocational training settings:

- Staff information, advice, and guidance on AS/HFA;
- Awareness training for all staff (including Disability Officers) of each educational/training institution (post leaving certificate, further/adult and higher education and vocational training);
- Links to share information and clarify roles of responsibility should be developed between disability officers, counselling staff, career guidance counsellors, vocational training staff, parents and local ASD intervention services;
- The Department of Education (DES) and Science and the Department of Health and Children should develop a one hour overview and information/awareness package on AS/HFA for distribution to vocational

training staff, post secondary, further/adult and higher and vocational training/education institutes;

- Disability Officers, student counselling services staff and other staff members with responsibility for individuals with AS/HFA in education/training institutes, should be placed on mailing lists for inservice training sessions, seminars and workshops held by Aspire, DES and related bodies;
- Consideration should be given to the problems encountered by these students as part of the teaching/learning process.

3) Availability of Materials on the identification and methods of support for students with AS/HFA and their Families

A booklet or series of printed information leaflets should be made available to families and/or students with AS/HFA who are studying or intend to study at post leaving certificate, further/adult and higher education institutions. This publication(s) should contain information relating to the identification and methods of support available at their chosen institution. The guide(s) should be a self-help tool to college life, based on the experiences and advice of previous/existing students, staff and support organisations.

Specifically, the materials should contain the following information:

- Introduction to college life and life as a student with Asperger Syndrome – based on previous experiences from other students with advice about college life and other areas of concern such as how to understand bullying and overcome potential problems
- Strategies for successful studying – exploration of learning styles and how adults can cope within the higher level learning environment
- Ideas for getting started and keeping going – getting organised, getting started with course work and keeping going (personalised seminar timetable, weekly timetable etc)
- Ideas for effective communication – learning turn taking cues within the class, ideas for social interaction, communicating in tutorials etc
- Dealing with stress and pressure and where to look for help/advice
- Entitlements (Social Welfare) and Rights and how to use them
- Services available at chosen college/university and External resources available

Given the complexities in producing such a guide or series of guides, adequate funding should be provided for the complete cost of producing, printing and distributing these guides and to cover of the implementation of this material on the college websites.

Resources

Report of the Task Force on Autism, Department of Education and Science, 2001

Unilink Support Service, Trinity College Dublin

www.tcd.ie/disability/services/unilink.php

Students with Asperger Syndrome

www.strath.ac.uk/disabilityservice/informationforstudents/studentswithaspergerssyndrome

National Autistic Society

www.nas.org.uk/nas/jsp/polopoly.jsp?d=528&a=12205

Asperger Syndrome, Klin and Volkmar, 2000

Towards Success in Tertiary Study

www.services.unimelb.edu.au/edp/downloads/aspergers.pdf