



The Baily Thomas
Charitable Fund



Listening to students with Asperger Syndrome and best practice in higher education

Joanna Hastwell, AS Project Officer

email: joanna.hastwell@admin.cam.ac.uk

Collaboration: Autism Research Centre and Disability Resource Centre

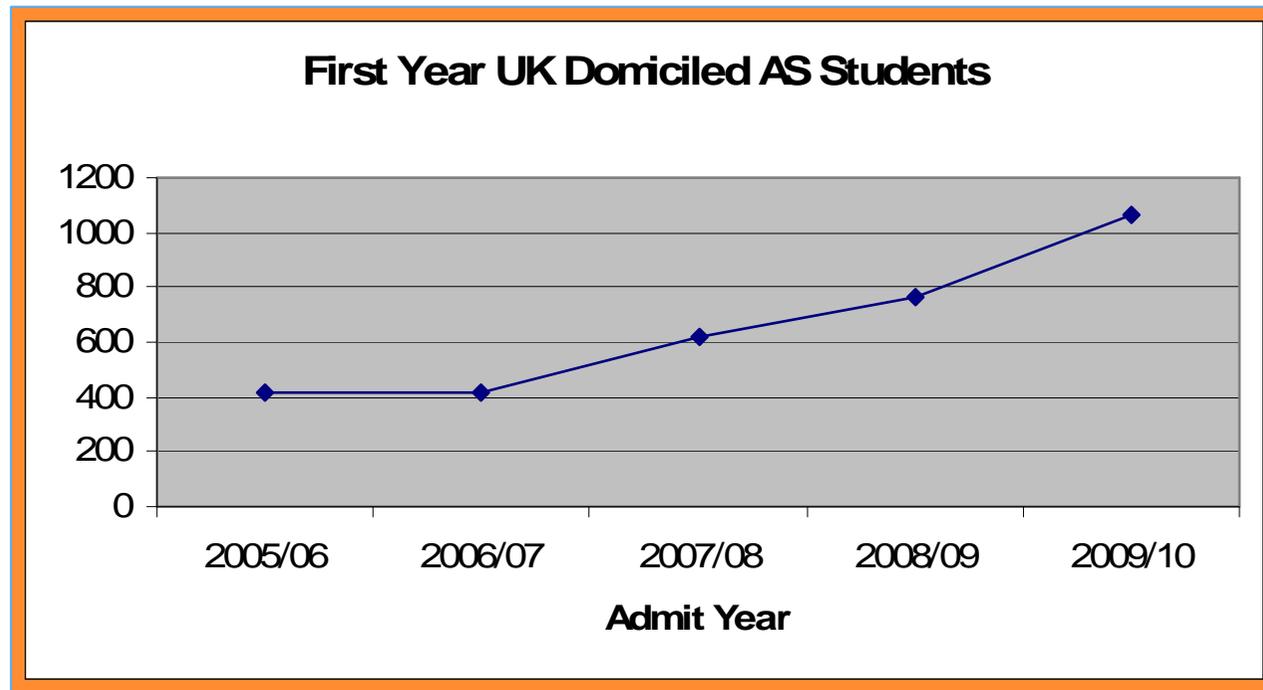
Project Background and Aims

- **Funded by the Baily Thomas Charitable Fund – started Aug 2009**
- **Collaborative project between CLASS (Cambridge Lifespan Asperger Syndrome Service) and the Disability Resource Centre (DRC).**
- **Project Steering Group: Prof. S. Baron-Cohen, Dr N. Martin, J. Hastwell and J. Harding**

Aims:

- **Service provision**
- **Emancipatory study**
- **Develop model of best practice**
- **Fast-track for diagnosis**
- **Build effective links between support services**

National higher education student data



Source HESA

2006/07 - 420 students with AS

2009/10 - 1065 students with AS – an increase of 154%

Research questions focused on:

- What is good / helpful?
- What is not so good / unhelpful?
- What would you like to see change?
- The students perspective on what is good practice.
- Personal experiences

29 student participants (10 female /18 male)

Cross-section of methods

Analysis

Thematic analysis:

12 categories were identified initially

Coded and grouped into **four** categories:

1. Social interaction
2. The University environment
3. Understanding of AS or HFA (self and others)
4. Engaging academically

Key finding 1. Social interaction (communication)

35% of students found social situations **'very'** stressful

Pertinent quotes:

“Am fine most times; am not fine when there’s a reason to find fault with myself”

“My main barriers have been social and I find large groups of people I don't know intimidating. As a result I rarely attend lectures and often feel very alone”.

“My hopes for the future are to do further study, a job in scientific research, maybe even having friends someday.”

Recommendation:

“Try to have well structured conversations, for example keep sentences short and clear.”

“An AS social group might well have helped in terms of providing an opportunity to make friends and do something other than just study all the time.”

“Say exactly what you mean. Do not exaggerate or try to put something such that it sounds less or more than what it is.”

2. The University environment



73% of students identified challenges because of their environment

Pertinent quotations:

“Being completely alone, and worse the lack of external structure and order”.

“I find it stressful having a room that is in the middle of a noise environment and studying in my room”.

“When I first started I had a lot of trouble adjusting to being away from home, spent all my time studying and did not make many friends. This lead to severe depression and having to take time out from my course”.

Recommendations:

“If supervising a student more than once try to schedule supervisions at the same time and on the same day of the week as each other”.

“Buy earplugs. Lots of them.”

3. Understanding of AS / HFA (self and others)



A lack of empathy from others was widely reported.

Pertinent quotations:

“Do not assume AS is something ‘wrong’ with someone. A lot of the problems are caused by a lack of empathy from others”

“AS means to me; organisation, directness, sense of purpose, being dependable and wanting others to be as dependable as I am. Lacking confidence with everyday tasks”.

“It explains how my brain works, and how **other** people behave in weird ways”.

“When someone with AS does something that seems totally ludicrous, they always have a reason which, in their own mind, is perfectly logical. It may be a good idea to ask them what this reason is”.

Recommendations:

“What I wish for would be the understanding rather than specific actions”

“Assume nothing. If I am anything to go by, there is no/few attributes of someone with AS”

“Remember empathy goes two ways”

4. Engaging academically



Pertinent quotations:

“If I am fixed on something, for example anxious about something that I need to do, I will be totally focused on thinking about that. This can result in tasks taking longer than would normally be expected.”

“I want to understand everything on a topic so I need to read every book that I can find that's got something on it. I suppose that's not a bad thing to read lots of stuff but this has caused me difficulties and taken up more time.”

Recommendations:

“It helps to have a mentor who is knowledgeable in my subject, having an understanding Director of Studies, having a contact at the Disability Resource Centre who is receptive to my particular needs.”

“It helps if I'm given lots of praise and encouragement – for me too much emphasis on mistakes and shortcomings can be counterproductive.”

“Avoid giving too much information at once, orally. Having it written down, or letting the person take notes, could be useful.”

Bigger picture

a) The Equality Act 2010 - recognises multiple identity

b) National Audit Office: *Supporting people with Autism through Adulthood*
5 June 2009.

- HESA data shows that over half the 1,455 students with autism in 2007-08 received DSA.
- Students with autism are more likely to get 1st or 2:1 especially if accessing DSA
- University is a major step for young people with autism owing to the change of routine, location and social environment. Without appropriate support they may not fulfil their potential and complete their degree.

The NAO report recognised University as a desirable option but this is not reflected strongly in The Autism Act and Strategy

Conclusions:

1. Early and anticipatory support is essential to avoid crisis
2. Students need incentives to declare AS in education and employment
3. HE and employment needs to be accessible and inclusive as a starting point
4. Good practice for students with AS is often straight forward and logical. Therefore it could be considered as good practice for all.
6. Student support recommendations should be transferrable into employment
5. Teachers and managers need training in understanding the needs of individuals with AS

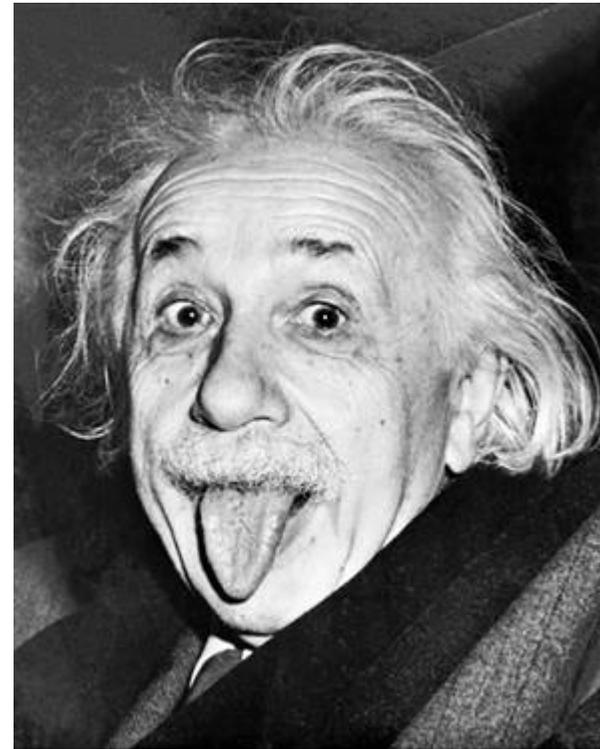
Our challenge:

To achieve:

‘Valuing diversity necessarily involves a degree of sensitivity from individuals and a cultural shift from the top away from tolerating, to facilitating, towards valuing’ (Beardon, Martin, Woolsey, GAP 2009).

Lets not forget that...

Students with AS at elite
Universities are by definition
very high achievers



References

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