Developing a diagnostic and support service for students with Asperger syndrome at university

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Introduction
About one per cent of children are estimated now to have an autism spectrum disorder (ASD) (Baird et al, 2006). Of these, many have intellectual abilities in the average or above-average range and are likely to be taught within mainstream settings. While the needs of children and their families are starting to be understood, services for older adolescents and adults are far less well developed. As increased recognition of ASD combines with rising numbers of all young people entering university (HESA, 2006), a new challenge emerges: how to assist those with ASD or Asperger syndrome (AS) in their progression through college or university. In addition, to meet the requirements of the Discrimination Disability Act (2005), universities have to anticipate the support and adjustments that students with disabilities may need rather than just being reactive when difficulties arise. In this paper, we report on the service that is evolving at the University of Reading to meet the needs of our students with Asperger syndrome, a service that has been informed both by our early experiences of students in the University and the emerging literature about the needs and outcomes for adults with ASD.

Without appropriate support, outcome for many individuals with Asperger syndrome in adulthood appears to be bleak. While there may be improvements in language, the social impairment is long term (Beadle Brown et al, 2002), impacting particularly on friendships and other social relationships and the ability to gain meaningful employment. Summarising a broad range of studies following up more able individuals with autism or AS, Howlin (2000) noted that although outcome was highly variable, ‘good’ outcome was reported for a maximum of 44 per cent of more able adults with autism or Asperger syndrome. At best, no more than half were in work, with one study reporting only 5 per cent of their group in employment. About the same proportion were living independently. Psychiatric disturbance ranged from 11 to 67 per cent, the most common being depression and anxiety disorders. Although prevalence is hard to establish, rates of these mood disorders appear to be higher in the population with ASD than in the general population (Kim et al, 2000).

The needs of adults with AS are wide-ranging and include help to participate in appropriate education and employment, support with living arrangements and assistance in developing a good social network. Two keys to good outcome in adulthood are consistently reported in the literature: early diagnosis (Rogers, 1996) and provision of appropriate support (Howlin, 2000). Many individuals with AS are diagnosed late, with an average age of 11 years, and diagnosis in adolescence and adulthood is not uncommon (Howlin and Asgharian, 1999). For these individuals, opportunities for intervention in childhood will have been missed, but even for those who do have a diagnosis, professional services are limited (eg PHIS, 2001) and support in terms of finding jobs and accommodation is usually provided by families (Howlin, 2000).
It is well recognised that at present only a small number of individuals known to have AS attend college or university (Howlin, 2004), but with better early intervention and support numbers are likely to increase and indeed this is happening already (HESA, 2006). Currently in the University of Reading, about 0.2 per cent of undergraduate students are known to have a diagnosis of ASD, clearly fewer than would be predicted by estimates of prevalence of ASD in the non-learning disabled population. The support needs of these students are clear, ranging from exam preparation and project completion to housing and relationship difficulties. In the following paper we outline the way the service has developed at the University of Reading to try to meet these academic, social and emotional needs and describe and reflect on the first year of our current team approach to supporting students.

Development of the service

Initial attempts: unfocused support

Until the specialist service at the University of Reading was set up, the particular needs of our students with Asperger syndrome were not being met. Some students with AS were diagnosed as having dyspraxia and odd social behaviour and they received support for their academic work. However, the impact of their social difficulties was underestimated and their frustration and increasing isolation led to an escalation of emotional difficulties and dysfunction.

Academic difficulties were often the first to be recognised. Students who failed to hand in coursework, were poor in timekeeping, had sporadic attendance and exhibited eccentric behaviour were perceived by academics to be idle or insolent or both. Tutors frequently responded with a disciplinarian approach that was either unhelpful or detrimental. Despite hours of tutorial support, several academically able students failed their courses and left the university.

Odd behaviour in halls of residence also attracted attention. Several students, both male and female, misinterpreted platonic friendships for budding relationships and were accused of making inappropriate sexual advances. One student disabled an alarm system because he was sensitive to the buzzing. His Hall Warden issued a warning and financial penalty due to the buzzing. His Hall Warden issued a warning and financial penalty rather than taking the time to understand the student’s behaviour. This was unhelpful.

When a student with a formal diagnosis of Asperger syndrome entered the University, the Counselling Service started to learn about AS and gradually became aware of other students within the ASD spectrum. At first the support consisted of regular weekly one-to-one meetings with a psychologist and liaison with a personal tutor but it was soon found that the tutors had neither sufficient time nor the expertise to provide appropriate support. It was found that regular individual mentoring was beneficial for helping with day-to-day social and organisational difficulties for maintaining motivation and for ensuring that small incidents did not develop into crises that could lead to depression and/or excessive anxiety. Three main support requirements were identified: social difficulties, academic difficulties and emotional needs. However, to fund the mentoring, a formal diagnosis on the autism spectrum was required.

It soon became apparent that there were students who were failing to cope and appeared to be on the spectrum but arranging diagnostic assessment for them was very difficult. An early step was the development of a diagnostic service to enable support of all those with ASD in the University, not just those who arrived with this label. It was fortunate that one of the authors (FJK), a lecturer in the School of Psychology, works in a social communication team in the NHS and thus had the necessary expertise to run such a clinic for the University.

Diagnostic assessment clinic

Funding the clinic

Individual assessments are funded via the Access to Learning Fund, which means that the student must be in receipt of a student loan. Clinic start-up costs (such as leaflets and an information pack) were funded by a grant from the University’s Annual Fund.

Accessing the service

This currently operates via a closed system such that students do not find out about the clinic other than through work with a counsellor or study advisor; direct self-referrals to the clinic are not possible. Once the initial idea has been raised, students meet with the academic study advisor (the first author, AMT) to discuss the assessment. This gives them the chance to think through the pros and cons of a diagnosis and to ask questions. Students are given a leaflet containing information about the clinic and diagnostic process and outlining the implications of a diagnosis. If they decide to proceed, they complete a form giving consent to the assessment, which involves contact with a parent or older sibling (to provide the necessary developmental information) and an individual nominated by the student who can provide corroborating
information. The student is formally referred to the clinic by their GP, thereby giving them another opportunity, if required, to discuss the assessment. This helps to ensure that the student has thought through some of the implications of the assessment before they attend.

**Diagnostic assessment**

As there are few instruments suitable for adult diagnosis (Baron-Cohen et al 2005), the National Autism Plan for Children (NIASA, 2003), which sets out guidelines about best practice with children and adolescents, was used to inform the principles of the assessment. These include involvement of ASD trained personnel, a multidisciplinary approach, co-ordinated information from all settings, ASD specific developmental history, face-to-face observation, communication assessment and screen for co-morbid mental health problems.

There are three stages to assessment. The first is the collation of information about the student from the individual nominated by them (generally a University counsellor, study adviser or personal tutor). This interview is completed by telephone and comprises information about the student’s social communication skills and academic and daily needs. In the second stage, the student and his/her parents attend an assessment clinic conducted by FJK, the clinical psychologist and a speech and language therapist with experience of children and adolescents with ASD. A comprehensive developmental history is taken from the parents with contributions as appropriate from the student who is present during the interview. The student is interviewed alone about their strengths, experiences and difficulties at University. This informal interview provides an opportunity to assess the student’s social communication skills and to ask about their understanding of concepts such as friendship and other relationships. A screen for mental health difficulties is carried out during this interview. Finally, the students and parents are invited back for feedback about the diagnosis and a series of recommendations covering social, academic and emotional well-being for the immediate future at university and beyond are jointly agreed. Students who receive a diagnosis on the autism spectrum are given an information pack about ASD that includes sources of further information and support both at University and outside. They are also given a recommendation to contact their counsellor or study advisor for a follow-up appointment as soon as possible to debrief.

**Team support**

Each student with a diagnosis of AS has access to all the usual university support services in addition to an individual mentoring service: the Disability Service, the Academic Study Support Service, the Counselling and Psychological Services, the University Medical Practice and the Careers Advisory Service. However, a student with AS may need help to access each service at the appropriate time and it is vital that the individual service provider recognises specific individual needs and has the knowledge to respond appropriately.

Practice showed that some individuals were getting regular support from all services but the advice and guidance they received could be confusing and was sometimes conflicting. Others were falling through the referral net. The ASD Co-ordinating Team was formed in order to improve and co-ordinate the support system and to inform practice.

**Professional co-ordinating team**

The team comprises FJK, a Consultant Clinical Psychologist with expert knowledge of AS (also a lecturer in the University’s School of Psychology), AMT, the Academic Study Adviser (also a psychologist), the Head of the University Counselling and Psychological Services, a Disability Officer, the University Mental Health Adviser, a Careers Adviser and a GP from the University Medical Practice. The team role is fourfold:

- to respond to the difficulties of the individual student and oversee the mentoring support
- to monitor the individual student’s:
  - academic progress (direct contact with academic tutor)
  - health
  - emotional well-being
  - social skills needs
  - career preparation
- to train academic and support staff to respond appropriately to students and staff with AS
- to provide consultancy to academic departments, halls of residence and parents

Each student is assigned a keyworker, who is usually a member of the ASD coordinating team. The keyworker will respond to immediate needs, refer to other services and maintain the monitoring role. By meeting regularly and discussing the needs of the individual students the professionals can pool their understanding, formulate useful interventions and record actions and outcomes to develop a body of evidence-based practice.

**Mentoring**

Mentors are recruited from students in the University. Academic mentors, usually post-graduates from the
same department, offer support and advice to help students progress throughout their course. Social mentors are from a different department and assist with social integration via jointly attending social events and providing a chance to debrief. Mentoring is funded via the Disabled Student Allowance which is available for UK students with a formal diagnosis of AS or ASD. In addition, Local Authorities require an independent Assessment of Need from an Access Centre to quantify and price the actual requirements.

**Structured support for mentors**

In addition to their initial briefings, the mentors are invited to group supervision meetings, twice per term, with the Disability Officer, the Academic Study Adviser and the Clinical Psychologist. Common problems are discussed as a group and suggestions for good mentoring practice are developed. Confidential problems relating to deviant behaviour, problem relationships, health and sexual matters are discussed in individual consultations with the professionals. When individual safety and matters of urgent concern are raised, such as a vulnerable female planning to attend a venue where she may be at risk, the mentor can immediately consult the Disability Officer who may consult with colleagues and intervene as necessary. Training and support for mentors is still evolving and there is scope for developing good practice.

**Involving parents**

The supporting role of parents in a student’s transition from home to university is acknowledged and welcomed. Parents and student often attend pre-university meetings with various support and academic staff and the student is encouraged to give written permission for oral and written contact between parents and a coordinating team member to be maintained during their first year. Often, when unable to tell anyone else, a student will email or phone a parent and talk about problems. The parent can alert the keyworker so that the difficulties can be addressed. Typically, the student will attend a regular meeting saying that all is well and will not mention any concerns unless they are raised by the support worker. Once the problem is addressed, their quality of life and ability to study may improve significantly. As a general rule, contact with parents decreases as the student learns to trust their mentor and the professionals and, by the final year, regular contact with parents is rare.

**The needs of students with AS**

The closely co-ordinated approach to supporting students with AS in the University of Reading means that their social, academic and emotional needs can be monitored and a range of interventions offered as appropriate.

**Meeting needs for social support**

Adapting to university life in a vast institution, with crowds of new people, confusing demands and peculiar rules, can be an intimidating experience for all new students; for students with AS, the task of adjustment can be overwhelming. The social mentor can help to mediate both practically and emotionally.

From the outset the mentoring relationship is explained so that the student is not under the illusion that the mentor is a friend for life. The initial task is to help the student to settle in by working out routes around the campus and guiding them through the maze of registration and the Freshers’ Fair. In company with the mentor the student can attend the first meeting of a society, sports or interest group.

Most freshers want to make new friends. The student with AS desperately wants to make new friends too, but may not have the skills and ability to do so. To make it even more difficult some students will recoil from association with anyone who appears to be ‘geek or freak’ (Jackson, 2002) for fear that their own attractiveness will be diminished (Brown, Mory and Kinney, 1994). Others will offer company, although this may backfire.

A mentor cannot help in all circumstances, but at least there is someone to debrief the student later.

**Everyday living**

Setting up routines and procedures can stabilise everyday living arrangements. Establishing how and when to do the weekly laundry and explaining the protocols for sharing a fridge and kitchen can be very important. The student with AS, who perceives six chocolate biscuits in a tin as an invitation, may be surprised by the ranting of a new ‘friend’. Entering a

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**Paul was taken to the Union bar by new acquaintances in his hall of residence. At the bar the proximity of other bodies jostling to be served, together with the noise, made him feel uncomfortable and anxious. Once served, he had to concentrate on not spilling the drinks. Suddenly he was accused of leaving without paying. Paul’s embarrassment, indignation and anger began to mount and he realised that he had to leave immediately if he were not to lose control. He could not return to his new friends and he never went back to the Union.**

A mentor cannot help in all circumstances, but at least there is someone to debrief the student later.
dining hall filled with noisy students may be daunting for many, especially when there are odd customs to observe. Negotiating the canteen system and choosing somewhere comfortable to sit is much easier in the company of a mentor. The social mores can be explained and the form of acceptable greetings can be modelled so that a student with formal speech can learn to substitute ‘Hi’ and ‘See you’.

Those with AS are likely to make acquaintances rather than close friendships. However, as the terms roll by, they will recognise that others are making friends and that they are feeling lonely. While a social mentor is not a friend, a twice weekly meeting for a game of table tennis or a cup of coffee can make the term more bearable.

Some students are happy to relinquish their social mentor after a little while. Others enjoy the security of a continuing relationship, even if the mentor changes every year. The mentor may be able to help negotiate changes, whether it is a timetable alteration, or accompanying on a field trip, during which the anxieties caused by the challenges, alone, could outweigh any educational benefits. Where an individual is still learning to be independent the mentor may be helping to teach skills. In some environments where other students are immature or unthinking, the social mentor may help to negotiate situations that may otherwise develop into bullying and harassment.

Meeting academic needs

The overall responsibility of the academic mentor is to help the student to keep up-to-date with studies, to hand in assignments by the deadlines and to prepare for examinations. Although these sound like skills the student should bring from school or college, the lack of structure at university and the emphasis of independent learning make the tasks more challenging.

The student with AS, usually lacking a social network, may have no one from whom to borrow notes after missing a lecture and no one to discuss exactly what is required when instructions are unclear. If they fail to understand a vital area of work they may be reluctant to ask for help from fellow students or staff. Prompt support from a mentor may reduce anxiety, which might otherwise lead to depression and further inhibit the student’s ability to learn.

Typically, the student with AS lacks conventional motivation and is easily distracted from routine ‘boring’ tasks. Unable to comprehend the importance of foundation work and the need to practise skills, the student may ignore what appears to him to be a pointless assignment.

Overrunning deadlines and failing to hand in work are common problems.

Tom aimed for perfection and he was aware that there were strict penalties for late work. He reasoned that since he had not finished the questions there was no point in completing these and submitting it late. Fortunately, a lecturer met him by chance and enquired about the missing assignment. Tom produced the partly completed paper from his bulging case. The work was good enough to be awarded a first.

For some students the penalty rules prove more of a deterrent than a spur and it is frequently recommended that students with AS are not penalised. For others, misunderstanding communication can result in failure to pick up helpful hints.

Samantha explained that all through school she was convinced that the work presentation style she had been taught initially was the right way. She did not recognise that different styles introduced by a new teacher could lead to better marks for coursework nor did she understand the subtle cues, picked up by other students, about which areas were likely to come up in the examinations.

The most common difficulty appears to be understanding instructions for assignments and the underlying purpose of the assessment. Unable to understand another person’s perspective, the student does not appreciate what needs to be demonstrated in an assessment. Typically, he states that the complex computer programme he has developed or the working model he has produced shows that he understands his area of work. Why does he have to write 30 pages to explain the background to his work and the problem he is addressing? He may need weeks of coaxing and motivating to produce the written work that fulfils the academic requirements.

This description can give only a flavour of the difficulties faced in regard to academic work. There are also particular difficulties with participating in group work and in giving oral presentations. Maintaining motivation is vital. As long as the work output is being monitored, so that the student does not fall too far behind, difficulties can be tackled as they arise.
Meeting emotional needs

The pressure on individuals with AS to maintain a social front of learned behaviour for hours on end to fit in with everyone else’s expectations can be very draining, both physically and emotionally (Molloy and Vasil, 2004). Just remembering to control tics, to give eye contact and to respond to smiles and greetings can be hard work when it does not come naturally. Sometimes a student with AS can cause offence inadvertently; more often they can be offended or angered by behaviour and remarks that have been misunderstood or taken out of context. At such times they need space to be themselves. Playing music loudly, physical exercise, drawing, retreating to computer games are some of the individual ways to cope with pent-up stress. Many also find it helpful, later, to talk through what has happened with their mentor so that together they may be able to understand it.

In addition to all the difficulties associated directly with AS, there are the usual developmental stages of adolescence to be negotiated. This whole area, including separation from parents, sexuality and relationships, may require much talking through and the professional expertise of a counsellor or psychologist can be very helpful.

Despite the best-intentioned support many things can go wrong for a vulnerable adolescent. A difficult area of academic work can cause concern; a boyfriend/girlfriend relationship may come to an end; a thoughtless remark from a staff member can cause anger and embarrassment. A couple of minor difficulties can very quickly escalate into full-blown emotional turmoil resulting in anxiety disorder, perhaps an increase in obsessive-compulsive behaviour, or depression, which may result in retreating to the bedroom and a downward spiral.

While providing support for daily living and academic progress, mentors informally monitor general health and emotional well-being. They are given some training to recognise depression and excessive anxiety and can alert the Disability Officer if there are concerns.

First year of the support service

The first full year with the co-ordinated service has been interesting and thought provoking. Our chief impression is that a diagnosis in combination with focused support is helpful to students. Five of the students who have had mentors have left the University with good degrees. In contrast, with the benefit of hindsight, there were at least six students who probably had AS, who failed the first year of their course and were unable to progress, despite being given some help.

Acknowledging the diagnostic label has been important both for students and their tutors. It gives students the ability to access the wealth of helpful material about living with Asperger syndrome that is now emerging on websites and in books (see Murray, 2005). Diagnosis also seems to reduce feelings of isolation, giving an explanation for ‘difference’ that many students find reassuring. For tutors too, the diagnostic label gives ‘permission’ not to be alarmed or frustrated by a student’s problematic social and organisational skills, which may otherwise be perceived as disinclined and even arrogance.

As well as recognising the diagnosis of AS, developing a service that is flexible, focused and able to respond to a student’s needs as they arise has been paramount. Not every student wants support and both sorts of mentoring throughout their time at university. Commonly, more academic help is needed in the final year, particularly around the completion of projects and preparation for Finals. Monitoring has therefore become vital in ensuring that students can rapidly access the support they need, before a difficulty becomes entrenched. The time spent in termly co-ordinating meetings has proved invaluable in ensuring students do not slip through the net, with each member of the team believing that another is dealing with the situation. Taking collective responsibility for students is reassuring for the whole team.

Concluding comments: a note of caution

Diagnosis comes with responsibility to provide appropriate and focused services. The numbers of students with a diagnosis has increased each year and this raises the main dilemma facing the team. Providing this level of support is costly in terms of time and resources. Student needs are better met now than previously but developing the team has undoubtedly placed a burden on already stretched services. A second dilemma is that academic and practical needs (such as housing) are easier to meet than social and emotional needs and, as yet, the evidence base for working with able young adults is rather small. Students with AS may be reluctant or even unable to seek help and it is difficult to balance a recognition of their needs while respecting that they are autonomous young adults. Similarly, assisting students in their transition to the workplace, where supports are still few and far between, is problematic. The need therefore to evaluate the effectiveness of this approach and
to resource and fund a properly funded team in the near future is paramount.

References


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