



University Challenge:

**Integrating Care for Eating Disorders
at Home and at University**



Acknowledgements

We wish to thank all those who took part in our surveys and supported the compilation of this report. We thank Professor Janet Treasure, Dr Tom Lubbock, Dr Andrea Pickering, Simon Thompson, University Mental Health Advisory Network, Berkshire BHFT Trust, Brighton and Hove Eating Disorder Service.

We thank the Executive Committee, Rosanna Hardwick, Rosie Tressler and Sara Fernandez at Student Minds for their help in delivering this report.

This report has been produced by Student Minds

Student Minds is a national charity that works to encourage and enable peer support for mental health, helping students to have the confidence to talk and to listen. We aim to bring people together to share strategies for managing mental health; to talk honestly in a safe and pro-recovery environment. We provide passionate students with training, support and supervision to enable them to run peer support groups at their Universities.

About the authors

Ms. Eleanor Hambly

Ms Hambly is an Assistant Psychologist for Berkshire CAMHS. Ms Hambly has been an active volunteer at Student Minds since 2010, she was appointed to the board of trustees at Student Minds in 2012.

Dr Nicola Byrom

Dr Byrom is a researcher at the Department of Experimental Psychology at the University of Oxford and the founding director of Student Minds.



Contents

Acknowledgements.....	1
This report has been produced by Student Minds	1
About the authors.....	1
Contents.....	2
Executive summary	3
Our key messages:	4
Methodology.....	6
Introduction	7
Expectations and reality.....	9
Moving to University.....	10
Accessing support as a university Student.....	12
Referral to specialist services.....	14
Waiting lists.....	15
The transient nature of student life.....	16
Registering with both home and university GPs at the same time	18
Key recommendations	21
References	23

Executive summary

The NHS has values and expectations that it is required to meet, but are these met in reality? The white paper 'Putting People First' (HM Government, 2007) states that the NHS has a duty to provide effective, integrated and personalised services, but does this happen? This report investigates whether the NHS are meeting their duty of care for university students with eating disorders. It highlights the lack of integration, personalisation and effective care provided for university students with eating disorders when they transition between home and university.

Moving to university is a difficult time, a time when mental health problems are likely to develop (Royal College of Psychiatrists, 2011). Students are moving away from their support networks and potentially away from specialist services where they have established therapeutic relationships with clinicians. It is therefore a crucial time for the delivery of support to students and yet there are few mental health services providing targeted support for their needs (Royal College of Psychiatrists, 2011).

As well as the initial move away from home, students also live very transient lifestyles, often living at home during the holidays and at university during term-time, which can mean spending over 25 weeks of the year at home. This can be difficult for students as demonstrated by quote *a*. Currently students can only be registered with one GP surgery at a time. This results in

students living in an area where they are not registered with a GP for a large proportion of the year. The complications faced by students seeking care when they are a temporary resident include the need to fill out multiple forms, poor access to the patient records, not being allowed blood tests and having to explain their history to a new GP, which can be traumatic.

Further problems arise if a student requires specialist care. Due to the high demand for psychological therapies, it can often take a long time to move up the waiting list to receive care. It is common for students to reach the top of the waiting list in their university locality when they are back at home during the holidays or when they are about to sit university exams. If patients cannot attend the sessions assigned to them, they are usually dropped off the waiting list. Once removed from the waiting list students then need to go through the referral process and effectively start again. A further issue is that people with eating disorders often

"Transitions between home and university were also the most difficult times for me, when I was most likely to relapse irrespective of the difficulties in transitioning between treatment teams - so it seems like a really important point to address." a

deny that they need help resulting in poor attendance and engagement with treatment. Services need to take account of this disadvantage and try to ameliorate it when managing waiting lists (Royal College of Psychiatrists, 2011).

The Handbook to The NHS Constitution for England (Department of Health, 2012) states that providing effectively integrated care to achieve better outcomes for service users in a cost effective way is a key priority for the NHS. However students often struggle, for the reasons cited above, to receive outpatient care, leading to deterioration in their health. The financial burden of poor early intervention is substantive: the total average cost of treating people with eating disorders as inpatients is about £50 million per year in England (Beat, 2012). The cost of treating outpatients with eating disorders is £3 million for England (Beat, 2012; Eisler et al., 1997). As well as the obvious economic benefits of successful early intervention, evidence shows it to be much more effective (Eisler et al., 1997).

In the long term solving these problems will require greater input from professionals. Professionals raised concerns about communication between different teams and the difficulties of passing on information (Leach and Hall, 2011). Professionals also raised concerns about the difficulty of referring and treating students with eating disorders. Student Minds research backs this up, with students reporting that they waited 18 weeks on average for an appointment with a specialist service. During this wait, 39%

of students felt that their mental health declined. Students reported that access to treatment from a specialist service is disrupted by moving between home and university. In this report we describe how technology has been used to support students through the transitions between home and university to reduce the disruption experienced. Students also felt that it would be helpful to be registered with both their home and university GP. This would prevent students having to register and explain their history multiple times, which can be upsetting and also lead to students withholding information. Being registered with two GPs will allow both to hold information on the patient. Having dual registration will also enable the student to have regular monitoring in both places, as certain services are not available as a temporary patient. This is particularly important when it comes to blood tests as these are a vital form of monitoring for complications from eating disorders, yet they are not accessible to temporary patients.

Our key messages:

Students should be able to register with two GPs at any one time

This would enable students to easily receive support at home and at university as they will only have to register once in both places. They will be assigned a GP at each practice, which could increase the continuity of care and reduce the risk that student's fall between the gaps. Dual registration

will make it easier for a student to be referred to suitable specialist services and ensure that appropriate monitoring of a student's health takes place both at university and at home. Having a named contact at each surgery will facilitate better communication between GPs and any other services involved in the individual's care. Dual registration will mean that both surgeries can hold copies of the patient's notes, allowing better record keeping and providing the GP with more information when seeing the student.

Appropriate care should be put in place before students arrive at university

As eating disorders generally develop in adolescence and early adulthood (Lucas et al., 1999), a proportion of students arrive at university with eating disorders. Moving away from home, and their specialist service, can result in these students receiving no support or follow up monitoring when they first arrive at university. The young person is often left responsible for registering with their university GP and seeking out necessary support. This is often a challenge for any student when they arrive at university, let alone a student whose eating disorder often means they try and avoid support.

Even if the individual makes pro-active steps to seek the support they are likely to need, it can take months for a referral to an eating disorder service to be processed. As such, the young person is likely to spend their first months at university with no support. This situation often arises despite the best efforts of the professionals who

provided the young person with support at home. The current structure of the NHS makes it difficult for professionals from one area of the country to request or arrange comparable support to be provided in another area of the country. Designing a national register with useful contacts such as GPs, specialist services, mental health advisors and support groups may alleviate the difficulties faced when trying to work out who to refer to or who to pass information onto.

Involve the student and, if appropriate, their families/carers in the decision process and copy them into all documentation to allow the student to take their records between services.

This is a simple way to allow easy transfer of information so that all support networks have a clear idea of the situation and the individual's care plan. Involving the student and their family in decisions may improve treatment plans, empower the student and family, and may increase adherence to treatment.

Methodology

Student surveys

Students with experience of eating disorders were invited to take part in a survey between May and October 2012. The students completing this initial survey were invited to participate in two further surveys, conducted between October and December 2012 and between January and March 2013.

Mental health professionals surveys

Surveys were sent to GPs and mental health professionals. The surveys were followed up with a series of short interviews.

Background papers

An extensive review of the literature on treatment for eating disorders and mental health provision for students in general was conducted.

Introduction

The fundamental thrust of this report is that university students with eating disorders are being let down by the NHS. The solution is very simple; students need to be provided with integrated, joined-up care.

Today, 49% of people aged 17 to 30 are in higher education (BBC, 2009). 78% of students live away from home for the duration of their studies, meaning that, on average, there are 1.3 million students who spend part of the year at home and part of the year at college at any one time (Leach and Hall, 2011).

Eating disorders generally develop in adolescence and early adulthood (Lucas et al., 1999) which is around the time that students move to higher or further education. This means that students may have an existing eating disorder when they move to university or they may develop it at whilst at university. In addition to the age of onset, research suggests that students at university develop eating disorders at a greater rate than the general population (Sell and Robson, 1998). Eating disorders are characterised by abnormal and restrictive eating habits to the point of self-starvation and severe, self-induced weight loss (Fairburn and Harrison, 2003). Evidence indicates that there are 1.6 million people in the UK affected by an eating disorder (NICE, 2004). Eating disorders have an overall mortality rate of up to 20%. This increased risk of premature death exists for all types of eating disorders (Arcelus et al., 2011).

Anorexia Nervosa is one type of eating disorder which is diagnosed when the BMI is 17.5 or less. Weight loss is self-induced and the person can utilise one or a combination of the following: self-induced vomiting, self-induced purging, and excessive exercise along with the use of appetite suppressants and/or diuretics. People with anorexia often have body-image distortion and experience physical problems such as loss of muscle strength (which also affects heart muscle), loss of bone density, impairment of linear growth and amenorrhea (loss of periods) (NICE, 2004; World Health Organization, 1993). Anorexia Nervosa has the highest mortality rate of any psychiatric disorder, with around 15% over 20 years (Sullivan, 1995).

Bulimia Nervosa is another type of eating disorder which includes a persistent preoccupation with eating; an irresistible craving for food where the person will consume large amounts in a short period of time. As a direct result of eating 'fattening' foods, people with bulimia nervosa use purging, starving and other strategies. The psychopathology includes a morbid dread of fatness and the patient sets

"In this time my problems got vastly worse because I had no support at all in the meantime and I had left my friends behind." *b*

herself or himself a sharply defined weight threshold (World Health Organization, 1993).

Despite the high prevalence of eating disorders amongst the student body, current efforts by the NHS to support these individuals are limited. Students receiving care from a specialist at home move to university and then need to register with a new GP. Following registration, they will be put on a waiting list to receive the same specialist care in their university town that they were already receiving at home. All too often, the outcome is that their condition deteriorates, resulting in a more severe eating disorder which is harder to treat. Systems need to be in place so that students are given a named contact before they arrive at university, whether this is a mental health advisor or a GP. It may not be possible to be referred to a specialist eating disorder service before moving to university, but making contact and registering with the GP at university will allow support and monitoring to be in place from the moment the student arrives. It can be incredibly difficult for professionals to know where to refer students in their own area let alone out of area. Therefore we recommend producing a national register of GPs, specialist services, university mental health workers and eating disorder support groups to enable better communication as the student is accepted into a university.

There will inevitably be students with eating disorders whose health deteriorates to the point where inpatient admission is necessary. Currently students are likely to be

admitted to hospital in their university town, leaving them at a distance from their family, loved ones and established networks of support. This leads to social isolation, compounding the mental health problem (see quote *b*, page 1). From our research it appears that the systems are not in place to enable students to receive consistent monitoring and support when moving between two localities. Although it may not be possible for students to receive face-to-face specialist therapeutic care at both home and university as a result of waiting times and the importance of developing a therapeutic relationship, other methods of support should be possible. For example monitoring of weight, mood and bloods is possible in both localities and is of upmost importance to identify early warning signs of deterioration. Online therapeutic tools may also provide continued and regular support. Possible tools for achieving this will be discussed below.

It is important to state that full recovery from an eating disorder is possible (Bardone-Cone et al., 2010) and that going to university can be a positive factor in recovery. However, early treatment remains an important factor in enabling people to make a full recovery (NICE, 2004). Safe treatment for eating disorders addresses all of the aspects of the illness: physical, behavioural and psychological factors and the need to provide collaborative care on an ongoing basis (National Eating Disorders Collaboration, 2012). Following discharge or transition between services, coordination and collaboration are particularly important (National Eating Disorders

Collaboration, 2012). Smooth transitioning and handover between treatment teams has been identified as imperative to ensure the sustainability of treatment outcomes (National Eating Disorders Collaboration, 2012).

Although recovery is possible, at present, fewer than 50% of adults suffering from Anorexia Nervosa will recover (National Eating Disorders Collaboration, 2012). Eating disorders are a complex and enduring mental health problem with substantive associated physical health risks. This means that continuity of care is of fundamental importance. Moreover, young people with eating disorders are reluctant to seek help and engage in treatment and so successful treatment may be dependent on healthcare professionals adopting a pro-active approach in getting young people into treatment and motivating them to persevere. The chronic course of eating disorders makes continuity and integration of care a necessity, but the transient and time-limited nature of student life can make continuity of care highly problematic (Quinn et al., 2009) without special consideration. The psychological nature of eating disorders means that they are most effectively treated with psychological interventions involving mental health professionals such as clinical or counselling psychologists and family therapists. These treatment methods rely on establishing a therapeutic relationship between therapist and patient, which is built on trust and continuity.

Expectations and reality

This report looks at the reality of care for students with eating disorders as a specific population and the unique set of challenges that they face. To demonstrate the disparity between the expectations of care and the reality of care for students with eating disorders, a number of research methods have been used.

As well as academic publications, Student Minds have used their collaborative expertise and research to demonstrate the difficulties faced by students with eating disorders and to provide recommendations in these areas. Two student surveys have been conducted by Student Minds: in a 'Students Referral Questionnaire', 33 students with eating disorders outlined their experiences at university. Of these, 30 students had spoken to a GP about their eating disorder and 27 students had received support from a specialist service. In a follow-up survey completed by 17 respondents, the students provided more specific information about the challenges they faced transitioning between home and university.

A qualitative study of GPs was conducted with practices in Brighton and Hove. Based on responses from the GP study, the 'Transitions Questionnaire' was developed and has been rolled out to healthcare professionals nationwide. The questionnaire was distributed through

the University Mental Health Advisory Network (UMHAN, a national organisation which emailed its members and these in turn e-mailed healthcare professionals with whom they had contact with), Berkshire NHS Foundation Trust (including Child and Adolescent Mental Health Service, Berkshire Eating Disorder Service and Adult Mental Health Service), Berkshire, Buckinghamshire and Oxfordshire Special Interest Group for Psychologists working with Children and Young People, and Student Minds who advertised the questionnaire on their website, newsletter and social media. There were 24 respondents to the Transitions Questionnaire. The sample was made up of twelve staff from University Counselling Services, three from a GP service, two from NHS CAMHS and seven from NHS Adult Mental Health Services.

The information from the range of sources described above will be used in the text below to explain the current situation of care for students with eating disorders and make recommendations to improve the care available.

Moving to University

The move from home to university is not only a stressful time for students, but also places considerable strain upon efforts to deliver continuity of care (see quote *a*, page 2). 70% (12/17) of students completing our follow-up survey had developed their eating disorder before moving to university. The Royal College of Psychiatrists (2011) recommend that the 'home' mental health team of a young person receiving support should make every effort to ascertain the service or services that would be appropriate for the patient and should then make the necessary referrals before the student starts at university. This is in line with The Handbook to The NHS Constitution (2012), which states that providing effectively integrated care and achieving better outcomes for service users in a cost-effective way is a key priority for the NHS.

Unfortunately, many university mental health advisors note that lots of their students arrive at university without a care plan in place. This failing is not necessarily the result of a lack of effort on the part of the home mental health team; mental health teams face a number of barriers, including uncertainty about who to approach at the student's university and a lack of knowledge about the support that may be available in the city the student is moving to (Leach and Hall, 2011). However, barriers such as these could and should be easily fixed, as it is vital

for students with eating disorders to have support in place before they arrive at university.

During the transition to university there is often another transition occurring for students between CAMHS and AMHS. The transition from CAMHS to AMHS has been referred to as problematic and even dangerous (Arcelus et al., 2008; Treasure et al., 2005). Without clear communication and care plans it is far too easy for students to 'fall between the gaps' of care (Treasure et al., 2005). With an estimated one quarter of patients in specialist adult eating disorder services being students it is a key concern that the services are providing adequate support and picking up all students with eating disorders (Arcelus et al., 2008).

NHS healthcare professionals, staff from University Counselling Services and GPs recognise that there are serious problems with the current systems in place to support students with eating disorders when they move to university. Of the professionals surveyed, 96% (22/23) felt that students do not get specialist care as quickly as they would like.

From the research in this section we recommend the following:

Appropriate support is put in place at university before the student arrives.

If a young person has recently been discharged from a specialist service or has been discharged from that service because they are moving to a different part of the country, comparable levels

of care or follow up monitoring should be provided at university.

Clear contacts to approach at a university with regard to supporting students with eating disorders.

University support services are usually involved in supporting a student with mental health problems. All universities should publish the contact details of appropriate support staff so that this information is easily accessible for health care professionals working outside of the university.

Clear, well-managed plans and good record-keeping to support the student through transition as well as other eventualities such as discharge or relapse.

Support for a university student with an eating disorder may span across organisations, with the involvement of university support services and professionals in the National Health Service both at the student's university and at home. It is vital that all parties be kept informed of care plans.

Clear communication and handover conversations between all those involved in the student's care.

Communication between all those involved in supporting a student is of vital importance to ensure the student is being monitored and provided with consistent care at both home and university. Effective communication will prevent students from falling 'between the gaps' and not getting the support they need.

Accessing support as a university Student

A major issue for students accessing support is the fact that, generally, the NHS is not adapted to the transient nature of student life. As a result of the lengthy times one can wait for specialist services, appointments are often offered to students who are either occupied with exams or away from their university towns for the holidays. Both of these inevitable elements of student life can disrupt the delivery of ongoing and lengthy therapies, which are common with treatments for eating disorders (Royal College of Psychiatrists, 2011).

The Transitions Questionnaire elicited the concerns of healthcare professionals. Only 13% (3/23) of professionals surveyed felt that they could support the *physical* health of a student with an Eating Disorder within their local health trust. Only 26% (6/23) felt they could effectively support the *mental* health of a student with an eating disorder within their local health trust. There are a number of reasons

"I was told by one doctor to 'eat more cheese' which naturally I found entirely unreasonable." c

"He [the GP] told me to go for a run to make myself feel better, even though the hospital had me on an exercise ban" d

why this could be, including not enough knowledge of eating disorders and poor communication and collaboration between services to provide all-round care for the student. Lack of service provision may be another factor and this is supported by the fact that GP practices are disadvantaged in the current 'payment by results' system (Royal College of Psychiatrists, 2011) which provides payments for treatment of specific diseases.

As well as the difficulties that professionals experience when supporting a student with an eating disorder, students also face barriers to seeking advice; in particular, lack of time and privacy concerns (Eisenberg et al. 2007). We surveyed students with eating disorders about their initial experiences of accessing treatment and found that many students are reluctant to speak to their GP about mental health problems. 22 of the 30 students who had spoken to their GP about their eating disorder reported having been concerned about going to see their GP. These students reported having concerns about whether their GP would understand them and take their problems seriously, and whether confidentiality would be respected (see quotes c and d).

From the research in this section we recommend the following:

Students to be able to register with their home and university GP at the same time.

This would enable students to receive support at home and at university, increasing the continuity of care and reducing the risk that student's fall between the gaps. We believe that dual registration will make it easier for a student to be referred to suitable specialist services and will ensure that appropriate monitoring of a student's health takes place both at university and at home.

Financial incentives for GP surgeries to treat university students and specialise in the challenges specific to this population.

Without financial incentives to support students, GP surgeries may lose the necessary provisions to provide care for students. If provisions are not there, GP surgeries may not build up a knowledge base of the specific requirements students have, resulting in care being less than optimal.

Improve the means to safely share patient information between services, especially between different trusts.

Improving the ability to share information will reduce the risk of important information being missed. Improved information sharing will mean that clinicians are in a better place to support the student and could also ensure that students do not have to go

through repeated assessment procedures before receiving care.

Further investigate the barriers experienced by professionals in supporting students with eating disorders and whether more provision of care is necessary.

This would give us a more detailed understanding of what prevents best practice being put in place for students with eating disorders. By understanding the barriers it will be possible to identify areas that need changing in order to best support professionals who provide care for students with eating disorders.

Referral to specialist services

The Royal College of Psychiatrists acknowledges that over recent years mental health services have been encouraged to focus on the needs of patients with 'more severe' mental health problems. This has contributed to a sense that it is increasingly difficult for students with 'less severe' problems to gain access to NHS services. The view that symptoms have to be serious to get support from specialist services is outlined by quote e.

"It reinforced my belief that I wasn't sick enough to need help [and] made me feel like I wouldn't ever be taken seriously so there was no point in bothering." e

There has been a move to try and increase support for those with less severe mental health problems. For example the IAPT programme (Improving Access to Psychological Therapies) in England and Doing Well by People with Depression in Scotland are two services provided by the NHS. However these services face similar problems in terms of their suitability for student lifestyles and, as the IAPT Data Handbook states, the programme is not

designed to support patients with mental health problems such as eating disorders (National IAPT Programme Team, 2011).

From the Transitions Questionnaire, 55% (12/22) of professionals did not find it easy to refer students to specialist services. We received feedback describing the difficulties some GPs experienced in referring to specialist services, such as knowing where to refer, knowing what the criteria were, completing a referral form and completing the necessary physical tests (blood tests and ECG monitoring). Difficulties experienced by not knowing where to refer could be alleviated by creating a national register for specialist services, support groups and other resources.

From the research in this section we recommend the following:

Create a national register identifying GP surgeries, eating disorder specialist services, mental health advisors, support groups and other useful resources in each area.

This will help healthcare professionals and students identify the support available to them in each area. It will allow healthcare professionals to communicate with professionals in different areas more easily as well as putting support in place for students at an earlier stage.

Waiting lists

As well as being more difficult to get a referral to specialist services students also have to contend with the often lengthy waiting lists. No one finds being on a waiting list easy. Of the students we surveyed about their experiences of an eating disorder at university, a quarter had waited more than six months for an appointment with a specialist service. Of the 27 students in our survey referred for specialist support, 16, that is just under 60%, had no contact with the service during the waiting period. On average the students had waited just 20 weeks for an appointment with a specialist service. This waiting period left some respondents doubting whether they needed treatment, which in some cases reinforced the belief that they were not ill and encouraged the eating disorder mentality of denial (see quote *e* page 8). This waiting period also resulted in some students feeling that their mental health declined, which in turn meant that some needed more intensive treatment (see quotes *f* and *g* on page 9).

"My uni GPs didn't seem aware of the ED even though I'd put it on my new registration form. It took me a full year to pluck up the courage to make an appointment and then I was told to come back next academic year... I spent a year on the waiting list for the [specialist eating disorder] service, I had one appointment during the summer holidays but as I'd have to travel from home to my university town for appointments I was ... put back on the waiting list until term started. I contacted the ED service in November as things were rapidly spiralling out of control. I was admitted to the inpatient and day patient ward in December where I've been ever since and have had to suspend my studies as a result. My university GP was supposed to monitor my weight the whole time but they never did and as a result no-one noticed I was crashing until my BMI became life threateningly low."

"I just got worse because I had no support and felt like I didn't deserve any." f

University Challenge

The transient nature of student life

Alongside the barriers that have already been outlined, the transient nature of student life poses further challenges. Moving back and forth between home and university can result in students not having a stable address, which in turn can cause problems accessing support from GPs and specialist services.

Students are often very aware of the problems that may arise if they register with a new GP at university. Of the students we surveyed, around a quarter stated that they had never registered with their university GP, which is a concern for several reasons (see quote *h & i*). Students who have not registered with their university GP might not have their physical and mental health monitored for 27 weeks of the year. Lack of monitoring can mean that early warning signs are missed, which may result in students only being seen when they are in crisis. If students are not accessing any support during this time, they may feel there is no one to turn to if they need support. Alternatively, if the students go back to their home GP for monitoring, they may miss lectures or university events, which may result in poorer grades, impaired future job prospects, stress and financial disadvantage (see quote *i*). Furthermore, for some it is not financially viable to remain registered with one GP for the entire year and

“On one occasion I had to fill out a registration form three times because each time I came back they still didn't have my name on their system. Because of the fact that I've registered, un-registered and re-registered with my home GP so many times, I've never consistently seen the same GP ... each time you have to explain your situation all over again - which is both stressful and frustrating.” i

“The main issue was trying to have blood tests during the holidays (to comply with my university doctor's treatment requirements), which I was told are not covered as a temporary patient...my only option was to re-register with them every holiday, or to go back to my university town for the tests (3 hours each way)... I ended up going back to my university town for all my treatment.” h

travel back for appointments, even if it would result in more consistent care.

Just under half of the students we surveyed stated that they had needed to access support from their home GP while registered with their university GP and 83% of these individuals reported that they had problems accessing support from their home GP. As in other areas outlined in this report, professionals also face barriers including restrictions around the transfer of confidential information between services (Royal College of

Psychiatrists, 2011). The detrimental effect of this barrier on a student's recovery in addition to poor communication between healthcare professionals, long waiting lists and inflexibility of care, is demonstrated by quotes *g*, *h*, *i*, *j*, and *k* (pages 8, 9 & 10).

Healthcare professionals supporting students with eating disorders recognise that there are serious problems as they move between home and university. Of the Transitions Questionnaire respondents, 92% (22/24) reported that students are negatively affected by moving between home and university in terms of their eating disorder treatment.

Further obstacles include the shortfall in case coordination for students with eating disorders. Research from the Students Referral Questionnaire demonstrates the active role students often have to take to get the support they require (see quotes *g* and *h* on pages 8 & 9. The National Eating Disorder Collaboration (2012) found that case coordination often falls to the family or the individual themselves. This places increased stress on the person and their family (National Eating Disorders Collaboration, 2012).

From the research in this section we recommend the following:

Students to be able to register with their home and university GP at the same time.

This would enable students to receive support at home and at university, increasing the continuity of care and reducing the risk that student's fall between the gaps. We believe that dual registration will make it easier for a student to be referred to suitable specialist services and will ensure that appropriate monitoring of a student's health takes place both at university and at home.

The development and use of secure online systems to allow easy transfer of confidential documents between services.

Improving the ability to share information will reduce the risk of important information being missed. Improved information sharing will mean that clinicians will be in a better place to support the student and may also mean students do not have to go through repeated assessment procedures before receiving care.

"There always seems to be a lag in transferring records between GPs and my records have been misplaced more than once" k

"I have had to go home for urgent appointments and taken time out of lectures a couple of times. It would have also made it much easier to manage my medication, my mum had to bring my medication from home every month." j

Ensuring the student and, if appropriate, their family/carers are involved in the decision process and copied into all documentation to allow the student to take their records between services.

This will ensure that the student feels empowered in the treatment process and could also allow easy transfer of information.

A case coordinator to be nominated well in advance of the student moving to university as someone who will meet with and build a trusting relationship with the student

By allowing the student to develop a trusting relationship with their case coordinator, they are more likely to disclose important information and seek support before crisis.

“Had I been registered with both home and university GPs, case notes such as treatment for mental health could have been passed between them, and there would have been no delays in getting appointments or prescriptions.”

Registering with both home and university GPs at the same time

Taking on board the evidence outlined above, in particular the difficulties in accessing GPs support at both home and university, we recommend that students should be able to register with two GPs at any one time. This recommendation is strongly supported by Professor Janet Treasure, an expert in the field of eating disorders. Student Minds research shows that 82% of students state that it would have been helpful for them to have been registered with both their home and university GP (see quote / page 12). In addition, 87% healthcare professionals (20/23) thought it would be beneficial for students to be registered with two GPs. Students would then have better access to support in both places throughout the year. For example, by being registered the students would be assigned a GP who they could see each time they visited the surgery, which would provide increased continuity. The surgery will also hold copies of patient records, providing better information for more informed care.

The cost

The inadequate provision of care for students does not only impact the individuals concerned, but impacts those supporting them. On top of the disruption to relationships and the stress imposed on all those involved, eating disorders also have financial implications. Unsurprisingly, the financial cost is significantly lower if people receive treatment for eating disorders quickly, than if that support is delayed (see quote *m* page 13).

If a student's eating disorder becomes so severe that they require inpatient care, the cost of this is on average £510 per bed-day and the average episode in hospital lasts 38 days (Beat, 2012). The total average cost of treating patients with eating disorders is about £50 million per year in England (Beat, 2012).

The cost of outpatient treatment, conversely, is on average £170 per attendance at 2011/2012 prices (Beat, 2012). NHS Hospital Episodes Statistics indicate that there were about 18,000 outpatient appointments for eating disorders in England in 2010. Therefore the total cost for outpatient appointments would be about £3 million for England (Beat, 2012).

If students have to drop out of university, society as a whole faces a cost. Rosenthal and Wilson (2008) found that mental health problems can have a significant negative effect on academic performance. They can decrease both emotional and behavioural skills, increase social isolation and lead to conflict and inadequate finances. "Mental disorders

create a substantial economic burden on our society... Drop-out from education will lead to diminished earning capacity and an increased risk of dependence on state benefits" (Royal College of Psychiatrists, 2011).

As well as the obvious financial benefits of early intervention compared to inpatient treatment, evidence shows that early interventions are more effective. If given an effective treatment such as family therapy within three years of illness onset randomised controlled studies have showed that 90% of patients had a good outcome at five years (Eisler et al., 1997). In contrast, only 20% of cases show a good outcome when treatment is given after three years of untreated illness (Treasure et al., 2005).

"On a waiting list with no support for months. My ED completely took over and I'm now facing needing much more intensive treatment than I did at original referral" *m*

Good practice

Although there are obvious and definite issues with the current support for university students with eating disorders, there is some exemplary work happening within the NHS. Described here are two innovative uses of technology which aim to support recovery in individuals with eating disorders. As well as the use of technology, there are support groups such as those run by Student Minds specifically for students with eating disorders. There are also a number of safe self-help books and online resources. Online resources may be particularly relevant for students, with 68% of 922 university students aged between 18 and 24 years indicating that they would use the internet for mental health support (Horgan and Sweeney, 2010).

The first innovative use of online technology is Support, Hope and Recovery On-Line (SHaRON). SHaRON is an online system that provides peer and clinical support. Moderators, including volunteer recovered individuals and clinicians, monitor the social aspect of the site where a supportive and recovery focussed atmosphere is paramount. This system allows patients to access support 24/7 around the globe. SHaRON enables patients and clinicians to book appointments and have online consultations. This system has been used effectively to support university students. In recognition of this success, SHaRON has become an EHI 2013 finalist. It is support like SHaRON that is designed with young people and a transient population in

mind which could be rolled out in other trusts to provide better support for their young service users.

The second innovation to be discussed here is the app Recovery Record. The app aims to offer anonymous 24/7 support for people with Bulimia Nervosa and Anorexia Nervosa. The app allows patients to connect with other users and clinicians for support. It is designed to complement therapy, offering a simple, discreet way to diarise feelings and log food consumption. The app is free to download and rewards use of the app with iTunes songs.

From the research in this section we recommend the following:

The use of new technologies to be used in all NHS trusts to maintain support with students whilst they are not in the area.

By using new technologies such as SHaRON and the Recovery Record, students will be able to have support throughout the year no matter where they are living. This will provide continuity and improve self-monitoring and self-help in students as well as providing easy ways to seek extra support.

Key recommendations

From the research outlined in this report the following key recommendations are made:

Students should be able to register with their home and university GP at the same time.

This would enable students to easily receive support at home and at university as they would only have to register once in both places. They would be assigned a GP at each practice which would increase the continuity of care and reduce the risk that students fall between the gaps. Dual registration would make it easier for a student to be referred to suitable specialist services and ensure that appropriate monitoring of a student's health takes place both at university and at home. Having dual registration will also enable the student to have regular monitoring in both places, as certain services are not available as a temporary patient. This is particularly important when it comes to blood tests as these are a vital form of monitoring for complications from eating disorders, yet they are not accessible to temporary patients named contacts at each surgery it will allow easier communication between GPs and for other services involved. Being registered with two GPs will allow both to hold information on the patient which will enable better record keeping and more informed decision making.

Ensure appropriate support is put in place at university before the student arrives.

Due to the average age of onset for eating disorders, a proportion of students arrive at university with eating disorders. Moving away from home, and their specialist service, can result in these students receiving no support or follow up monitoring when they first arrive at university. The young person is often left responsible to register with their GP and seek out necessary support. This may be a challenge for any student when they arrive at university, let alone a student whose eating disorder often means they try and avoid support.

Even if the individual makes pro-active steps to seek the support they are likely to need, it can take months for a referral to an eating disorder service to be processed. As such, the young person is likely to spend their first months at university with no support. This situation often arises despite the best efforts of the professionals who provided the young person with support at home. The current structure of the NHS makes it difficult for professionals from one area of the country to request or arrange comparable support to be provided in another area of the country. Designing a national register with useful contacts such as GPs, specialist services, mental health advisors, support groups may alleviate the difficulties faced when trying to work out who to refer to or to pass information onto.

student minds

University Challenge

22

Involve the student and, if appropriate, their families/ carers in the decision process and copy them into all documentation to allow the student to take their records between services.

This is a simple way to allow easy transfer of information so that all support networks have a clear idea of the situation and care plan. Involving the student and their family in decisions may improve treatment plans, empower the student and family, and may increase adherence to treatment.

References

- Arcelus, J., Bouman, W.P., and Morgan, J. (2008). Treating young people with eating disorders: transition from child mental health to specialist adult eating disorder services. *Eur. Eat. Disord. Rev.* 16, 30–36.
- Bardone-Cone, A.M., Harney, M.B., Maldonado, C.R., Lawson, M.A., Robinson, D.P., Smith, R., and Tosh, A. (2010). Defining recovery from an eating disorder: Conceptualization, validation, and examination of psychosocial functioning and psychiatric comorbidity. *Behav. Res. Ther.* 48, 194–202.
- BBC (2009). Students at home to cut costs. <http://news.bbc.co.uk/1/hi/education/7972586.stm> date accessed 30 July 2013.
- Beat (2012). Costs of eating disorders in England: Economic impacts of anorexia nervosa, bulimia nervosa and other disorders, focussing on young people. *Pro Bono Econ.* 1–37.
- Department of Health (2012). *The Handbook to The NHS Constitution for England.*
- Eisenberg, D., Gollust, S., Golberstein, E., and Hefner, J. Prevalence and correlates of depression, anxiety, and suicidality among university students. *Am J Orthopsychiatry* 77, 534–542.
- Eisler, I., Dare, C., Russell, G.F., Szmukler, G., le Grange, D., and Dodge, E. (1997). Family and individual therapy in anorexia nervosa: a 5-year follow-up. *Arch. Gen. Psychiatry* 54, 1025.
- HM Government (2007). *Putting People First, A shared vision and commitment to the transformation of adult social care.*
- Horgan, A., and Sweeney, J. (2010). Young students' use of the Internet for mental health information and support. *J. Psychiatr. Ment. Health Nurs.* 17, 117–123.
- Leach, J., and Hall, J. (2011). A city-wide approach to cross-boundary working with students with mental health needs. *J. Interprof. Care* 25, 138–144.
- Lucas, A.R., Crowson, C.S., O'Fallon, W.M., and Melton, L.J. (1999). The ups and downs of anorexia nervosa. *Int. J. Eat. Disord.* 26, 397–405.
- National Eating Disorders Collaboration (2012). *An Integrated Response to Complexity National Eating Disorders Framework.*
- National IAPT Programme Team (2011). *The IAPT Data Handbook: Guidance on recording and monitoring outcomes to support local evidence-based practice.*
- NICE (2004). *Eating Disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders.*
- Quinn, N., Wilson, A., McIntyre, G., and Tinklin, T. (2009). "People look at you differently: students' experience of mental health support within Higher Education". *Br. J. Guid. Couns.* 37(4), 405–418.
- Royal College of Psychiatrists (2011). *Mental health of students in higher education. Coll. Rep. CR166.*
- Sell, L., and Robson, P. (1998). Perceptions of college life, emotional well-being and patterns of drug and alcohol use among Oxford undergraduates. *Oxf. Rev. Educ.* 24, 235–243.

Sullivan, P.F. (1995). Mortality in anorexia nervosa. *Am. J. Psychiatry* *152*, 1073–1074.

Treasure, J., Schmidt, U., and Hugo, P. (2005). Mind the gap: service transition and interface problems for patients with eating disorders. *Br. J. Psychiatry* *187*, 398–400.

World Health Organization (1993). *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic criteria for research.*

**student
minds**

University Challenge

25

Student Minds

**16-17 Turl Street,
Oxford, OX1 3DH**

01865 264168

**hello@studentminds.org.uk
www.studentminds.org.uk
facebook.com/studentminds.org.uk
twitter.com/studentmindsorg**

We are kindly supported by Comic Relief, The Welton Foundation, UnLtd, The Matthew Elvidge Trust, The Charlie Waller Memorial Trust, The James Wentworth-Stanley Memorial Fund and Student Hubs.

Student Minds is a charitable company registered with Companies house, no. 7493445 and the Charities Commission, no. 114278