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TX: 13.02.03 YOU & YOURS - ANOREXIA

PRESENTER: JOHN WAITE AND WINIFRED ROBINSON

WAITE
Hello and welcome to the programme.

ROBINSON
Today we devote the whole of You and Yours to the eating disorder anorexia. No mental illness has a higher death rate, none has a higher suicide rate. More than a million people suffer from eating disorders, they often begin in adolescence and affect, in the main, bright young girls who are high achievers. One in five with anorexia will die as a result - a higher mortality rate than leukaemia. Yet specialist services are patchy and piecemeal.

Exactly one year ago Roz Dunham, who was 23, hanged herself in a cupboard off a psychiatric ward in the West Suffolk Hospital in Bury St Edmunds. She'd spent 10 years fighting anorexia and bulimia. Like many patients her case was complex and difficult, yet until she was 18 she'd had textbook treatment. Once she became an adult though she was thrown into the general mental health service where there is little specialist knowledge or treatment for people with eating disorders. Later I'll be discussing the lessons that can be learned from the death of Roz Dunham with a panel including the health minister Jacqui Smith. But first John Waite reports on a life and death - some parts of this story are very disturbing.

ACTUALITY - SCHOOL TOP OF THE POPS

WAITE
Children at County Upper School in Bury St Edmunds perform their own version of Top of the Pops as part of their charity fortnight. Today they're raising money for the Roz Dunham Trust, a charity set up in memory of a much loved former pupil.

VOX POPS
She was a party girl, she really was and I just think of her dancing like a mad woman, like really just like going for it on the dance floor.

I think she was a very courageous girl. I used to say to Roz I thought she was one of the toughest people I knew.

She was just so intelligent and incredibly sharp, very bright but so clever that she never made a point of it at all and just very sort of charming.

When she laughed she laughed and she threw her head back and she was really, really alive when she laughed and that's how I'd like to remember her.

WAITE

The Dunham family home is a beautiful deceptively large townhouse in the centre of Bury St Edmunds. Roz Dunham spent the last 17 years of her life there. Her father was an agronomist, who spent much of his time abroad, her mother, Gitti, a former nurse, is now a senior official with Amnesty International.

GITTI DUNHAM
Roz was a very happy child. She was born while we were living in Nigeria, her father was employed by the Nigerian government to do agricultural research and we lived there for eight years. But Roz lived in Nigeria for only the first four years of her life and we returned to England basically because we knew that they would have to be educated here. And very early on, I suppose from the age of three, it was quite evident that she was very bright, she was very academic, sensitive, creative, funny, extrovert.

WAITE
But that bright creative extrovert child turned into a deeply troubled teenager, gripped by a serious eating disorder which eventually led to her taking her own life.

GITTI DUNHAM
It was a sort of strange sense that you knew that everybody had given her up. And I have a feeling the reason why she actually committed suicide on the ward, because she could have gone outside, I think she did it on the ward because she wanted to show them that they didn't care.

WAITE
Roz Dunham's mental health problems first came to light at around the age of 12.

GITTI DUNHAM
We became aware that all wasn't well, when she was spending far too long on her homework, she was becoming obsessive with her homework and it was difficult to get her to bed at night because she was always doing her homework and it was when she had just started working on GCSEs that Genista, her sister, noticed that she was throwing away her lunches.

GENISTA DUNHAM
I suppose I did pick up on the first signs of her illness because I was with her more at school, I could see that she was becoming pretty fanatical about exercise, very funny about food, endless excuses, she seemed to pile a lot of food that she didn't want on to me which of course made me feel worse because I was going through that stage of I'm too big and I want to get thinner and things like that. I suppose it was those sort of ideas that she took on and took to an extreme.

GITTI DUNHAM
She was obviously losing weight, but it took hold really quite rapidly and quite perniciously, it was difficult really to get through to her after a while.

WAITE
Roz was first referred to her GP, then to adolescent psychiatrist and eating disorder specialist Dr Paul Laking.

LAKING
I first saw Roz in 1993 when she was about 14 - so 10 years ago virtually to the day. She'd had a problem for a number of months of losing weight and becoming obsessed with it and when I first saw Roz she was very withdrawn, head down, hair across her face and that was the sort of picture one saw of Roz when she was ill and that really contrasted with her rather bouncy, sharp, young person that one saw when she was better. Although she wasn't incredibly low in weight at that time, she actually was very low in mood and that was related to the starvation and so on.

WAITE
Roz was showing the classic signs of anorexia nervosa, a serious, potentially fatal, eating disorder. The condition's been around for centuries but wasn't formally described until 1873, in a paper by Charles Lasegue - L'anoxeie hysterique. Anorexics effectively starve themselves, often reducing their food intake to an absolute minimum. Dr Peter Webster is a consultant psychiatrist with the eating disorders unit at the Maudsley Hospital in South London.

WEBSTER
Anorexia nervosa has the highest mortality rate of any mental illness and is up to 20 per cent of sufferers over 20 years. In fact if an anorexic patient needs to be sectioned, they're that unwell, and treated under the Mental Health Act, one study suggests that 40 per cent of those patients will die over 20 years. About half of the deaths are due to medical complications and the other half due to suicide and the suicide rate is 200 times that of the populous.

WAITE
The precise root causes of the condition aren't known, though a number of theories exist including a genetic inclination to the illness and various psychological factors. People with anorexia are often obsessive and like Roz Dunham perfectionists. The uncertainty surrounding the causes of not just anorexia but other eating disorders, like bulimia and binge eating, makes treating them successfully very difficult. Dr Webster again.

WEBSTER
Well the average length of duration of anorexia is about six years and it can go on in some people for life. About 30 per cent of patients will recover, if they're adults, 30 per cent will sort of manage but have relapses and the other 30 per cent will have severe relapses and it will take over their life. Now the good news for adolescent patients is the earlier you get it and the earlier you treat it the much better the outcome. You can see improvement rates of 70, or recover rates of 70-80 per cent. So the need to get in there early and to treat early, to have assertive outreach and assertive treatment is a massive priority.

WAITE
In Roz Dunham's case her anorexia took hold to such an extent that her weight dropped rapidly and in May 1993 she was admitted to hospital as a medical emergency. She'd stopped eating altogether and had to be force fed through a drip. Her weight gradually went back up and she was allowed home but she soon relapsed.

GITTI DUNHAM
She was completely withdrawn, she was not talking very much or hardly at all and when she did it was in whispers. She had her hair all over her face and she would just sit in bed like that, without movement, without reacting. It used to take me about three hours to feed her a small carton of ice cream.

WAITE
So how low had her weight gone?

GITTI DUNHAM
I think her lowest must have been just over three and a half stone.

WAITE
In March 1994 she was admitted to Douglas House, a specialist adolescent psychiatric unit at the Ida Darwin Hospital near Cambridge. To begin with her prognosis wasn't good.

LAKING
The first time she went to Douglas House she was so ill and so determined, at that time, that I was genuinely compiling in my own mind what I was going to say to the coroner. I was genuinely fearful that she was going to die as a result of her very low weight. And at that time one obviously thinks well have I done absolutely everything I can possibly think of to enable Roz to get better and I couldn't think of anything else we could do and thankfully she stayed there and did gradually get better, gain weight and came out of herself more.

WAITE
One of her fellow patients was then 14-year-old Antony Pascal, himself severely anorexic.

PASCAL
Douglas House was unlike any other hospital ward I've been in before. It was run like a family really rather than a ward. People would have to take regular turns in cooking the meals, which is not done in normal psychiatric hospitals, keeping the place tidy and the nurses were very unlike any other ward I've been in before as well.

WAITE
Why is that?

PASCAL
They actually did take a notice in what you were doing, they would actually care if you were upset, which doesn't happen in psychiatric wards. If they applied that system to all hospitals then I think people would be a lot happier and would get better a lot quicker.

ACTUALITY - IDA DARWIN HOSPITAL

WAITE
Ida Darwin Hospital now has its own specialist eating disorders unit - the Phoenix Centre. It has 10 beds for adolescents with severe eating disorders and it's run by consultant psychiatrist Tony Jaffa, who also treated Roz. The ethos here is similar to that of Douglas House.

JAFFA
All the young people have education everyday, not as much as at school but not far off. There are a number of community meetings where problems in the day's routines are discussed. Of course mealtimes are a major focus because the young people here find it very hard to eat, so mealtimes can be quite stressful and there are a lot of staff around to provide support. Then for different patients there might be a range of individual or family therapies happening. Some of the patients require a lot of supervision to support them in not exercising or not nipping off to the loo to vomit after meals. But I think we try and create a pleasant atmosphere that is at least most of the time comfortable, occasionally it can get very tense.

ACTUALITY - IDA DARWIN HOSPITAL - CHILDREN SINGING

Having patients with different illnesses together does have some advantages but it has a lot of problems. If we're trying to treat patients with depression in the same unit as patients with psychosis, eating disorders, it's very hard to meet the individual treatment needs of the particular patients. Of course there are problems in having patients altogether too, that I have up to 10 patients staying at any one time on the Phoenix Centre, sometimes they all support each other to move forward and recover and they can be the most positive aspect of treatment experience for all of them, other times it's hell and they make each other worse and they compete to be the one who hides food most or eats most slowly and then it's rather negative.

WAITE
But specialist services, like the Phoenix Centre and the Maudsley Hospital, are few and far between. At the last count there were only 39 NHS units and 21 private ones. In October 2000 the Royal College of Psychiatrists published the most recent in-depth study of the provision of care for people with eating disorders in the UK, it concluded:

> **REPORT**
> Many areas outside the South East remain starved of services. Of existing clinics only half meet minimal criteria and spending on eating disorders is grossly inadequate.

And according to Dr Peter Webster, from the Maudsley Hospital, the patchy nature of specialist services means many people with eating disorders don't get the treatment they need.

WEBSTER
There's a dearth in most of the country, the South East has more than the rest, but even the South East doesn't have enough. The number of specialist children and adolescent eating disorder units is minute. One study showed that for adults, eating disorder patients, the mortality was significantly higher in areas that didn't have a specialist unit and yet a majority of the country doesn't have one. And in Wales and Scotland, for example, there are no NHS in-patient beds whatsoever for eating disorders.

WAITE
During her six months at Douglas House Roz's condition improved. She put on weight and was allowed home. But within a year her health had deteriorated again. As well as the anorexia she'd started harming herself and in January 1996, at the age of 17, she was readmitted to Douglas House. Where after another six month stay she improved to the point where she was able to return to school.

ACTUALITY - COUNTY UPPER SCHOOL

Paul Davis was then, and remains, head of the sixth forum at County Upper School in Bury St Edmunds.

DAVIS
I've got this vivid memory of her coming along, having been out of school for a time, and persuading us that she was well enough and she had what it took to come in. And it was really quite - it was quite heartrending really in many ways because she was so tough, she was tough on herself, she was firmly disciplined in many ways in the things that she was doing, which were hurting her, and you just couldn't help but have huge respect, she had a lot of courage, a lot of determination.

WAITE
Although she was still ill and subject to rapid mood swings, school friends, like Joanna Thomas, remember Roz with great affection.

THOMAS
Some of my best laughs from that age are definitely with Roz, I mean just had this ability to laugh at anything, I mean obviously a very black sense of humour, a very dark sense of humour which we all were a bit like. She also had this way of talking to you as though there was some kind of mutual understanding that you were very clever, whereas in fact you hadn't done anything to show that and it's very seductive when someone talks to you like that and very, very funny. And we used to get up to all kinds of pranks.

WAITE

The fact that Roz got such good psychiatric care as an adolescent was an accident of geography. A survey by Community Care magazine last year found that 80 per cent of social care professionals thought child and adolescent mental health services in this country were in crisis. There are only 900 beds in the whole of the UK, offering specialist care for adolescents with serious mental health problems. Peter Wilson, the director of the charity Young Minds, says many more are needed.

WILSON
By and large it's very much an under-resourced service. We know that there are a limited number of in-patient beds for adolescents and that far too many adolescents, particularly the young adolescents, end up in paediatric wards which are very often not the appropriate place for them to be or indeed in adult psychiatric wards, again which are very not appropriate.

WAITE
Roz's friend from Douglas House, Antony Pascal, happened to live in another part of East Anglia where this lack of specialist beds for adolescents meant he had to spend many months on an adult ward. His feelings of isolation led Antony to take desperate and deeply disturbing measures to try to get attention.

PASCAL
I'd take a razor blade and stroke myself with it as hard as I could really and made a huge mess of myself. The ward I was in, the bathroom, had to be closed down for three days because of the blood up the walls, I'd cut veins inside, I'd severed my artery and lost a lot of blood and my arm was black.

WAITE
You were lucky to be alive.

PASCAL
Yeah I was told I was lucky to keep my arm and for about six to eight weeks after my arm was paralysed because of the nerves that were damaged.

WAITE
And what was that all about - that was a cry for help?

PASCAL
That was to get some notice from the nurses really, to say look you're leaving me sitting here all day when I'm not well, this is me saying to you do something.

WAITE
Jill Burgoyne is a specialist eating disorders nurse based in East Suffolk. She says this sense of desperation is common amongst people with eating disorders who find themselves on a general psychiatric ward.

BURGOYNE
Having people say with low body weight anorexia on an acute psychiatric ward they get lost, they feel un-nurtured, they feel that it's difficult to get their needs met. And so they are discharged perhaps prematurely and sometimes that's when the problems can occur because there's always a gap - somebody being an in-patient to somebody actually being picked up by the community mental health teams.

WAITE
Roz Dunham did well for a time on her return to school, though her perfectionist streak meant she still had problems finishing her schoolwork. But then there was some low level bullying about her weight from younger pupils. Her mother says Roz was deeply upset by the name calling and almost

overnight her eating disorder changed from straight anorexia to bulimic anorexia - periods of starvation interspersed with bouts of binge eating often accompanied by heavy drinking to give Roz the courage to eat.

GITTI DUNHAM
With an anorexic you're desperate to make them eat because it seems so unnatural for anyone to refuse food. But with a bulimic I just couldn't keep any food in the fridge - there was no way that I could possibly entertain people or plan ahead without actually buying food that day and making sure that they had it before she could have access to it. It was problematic from that way because the food would just disappear and there wouldn't be anything left for anybody else.

WAITE
She would eat literally everything?

GITTI DUNHAM
She would eat literally everything. At her very worse she sometimes could eat right round the clock for several days - eat right round the clock and vomit in between - that's how bad she was.

WAITE
Roz left school at 18 with two A Levels, a disappointing result for such an obviously bright person. She took a number of temporary jobs, including working in a pub and also a care home. But her already unsettled life was further disturbed when she moved from the care of Dr Paul Laking and his specialist adolescent unit and into adult health services.

GITTI DUNHAM
She was seeing community psychiatric nurses, she was seeing psychiatrists - none of whom actually had any insight into how she was feeling. And I think when you've had very good care - which Roz had had - she recognised within the first few minutes, from the questions they asked, that they had absolutely no insight into her condition and lost confidence virtually immediately.

WAITE
The problems associated with this transition are widely recognised. For one thing there is no national cut-off point between adolescent and adult mental health services, in some places it's as low as 16 years, at other as high as 19. In some areas of the country many 16 and 17 year olds are excluded from both services because they're not in full-time education. And Peter Wilson, director of the mental health charity Young Minds, says there's also a big cultural difference between the two services.

WILSON
Any professional that's going to try and help these young people of this age - and we're talking 16, 17 upwards - should really address the issues within the individual but also be aware of what's going on in the family, what's going on in the university or in the job situation, it should take much more of an overall view of that person's life. Now I think that overall view has been very much a part of child psychiatry and child and adolescent mental health specialists generally but adult psychiatry tends to be more individual focused and tends to be more structured around diagnosis, medication, treatment and so on and I think that kind of approach doesn't really take in the family context or the complexity of needs and demands and aspirations that young people have at this age.

WAITE
And in its report on mental health services two and a half years ago the Common health select committee noted:

> **REPORT**
> The widespread and notorious lack of communication between adolescent and adult mental health services ...

And concluded:

> We believe that the current poor relationships between child and adolescent mental health services are highly unsatisfactory.

WILSON
Suddenly at 18 you don't change dramatically, these kind of disturbances are very much bedded within the personality and one can make a great deal of progress through the teenage years but very often they don't suddenly stop, they need the continuity of care, they need the continuity of understanding, they need the continuity of people mobilising themselves at the right time to help that particular individual.

WAITE
Unnerved by this sudden change in her treatment regime her mother says that Roz lost all faith in those who were supposed to be looking after her. She regularly missed appointments and gained a reputation as a difficult patient. In the midst of all this Roz's father was diagnosed with cancer, Gitti was now looking after two people and relationships within the family became increasingly strained. Roz's condition showed few signs of improving, though her close friend Kate Sawyer says Roz did, at times, seem determined to fight her illness.

SAWYER
One time I particularly remember is before I went travelling we sat down and were having orange juice in the pub, because she was in hospital at the time and she was on day release, and she just said that she really wanted to get better but said she didn't want to put on weight but she wanted to get better and she wanted to get better because her father was ill and she wanted to let him know that she did care, that she wanted to be alive, that she wasn't just hurting herself to hurt anybody, that she'd had enough of hurting people.

WAITE
But when her father died in June 2000 Roz's relationship with her mother Gitti hit an all-time low.

GITTI DUNHAM
Her life became completely chaotic. By chaotic I mean every time I heard the ambulance bell ringing I didn't know whether they were taking Roz to hospital. And she would come home at all hours of the morning and sometimes not at all overnight without telling me where she was and so many times she was taken into hospital either because she'd broken an arm or because she had just passed out. It was a nightmare. It was a nightmare which strangely enough I would willingly have back again.

WAITE
Roz was still bingeing and drinking heavily. Eventually in January last year she was admitted to West Suffolk Hospital as a medical emergency for treatment for severe liver damage. When she was physically recovered staff on the medical ward became increasingly worried about her psychological state and recommended she be moved to the psychiatric ward but her psychiatrist declined and said he'd look into alternatives. Four days later Roz was still waiting for a decision.

GITTI DUNHAM

Time and again the staff on the medical ward were trying to get hold of the psychiatric team to do something about her. She was really, really very low and she attempted suicide by trying to hang herself from the shower curtain on the medical ward.

WAITE
Roz was eventually admitted to the psychiatric ward where she was rated a low suicide risk. She stayed on the ward for five days. During that time her mood fluctuated dramatically, at one point she told nurses that she'd scouted round the ward looking for somewhere to hang herself but hadn't found anywhere. Despite this she wasn't reassessed for suicide risk. Then on the night of February 13th last year Gitti got a call from the ward to say that Roz had gone missing.

GITTI DUNHAM
On the Friday, which was two days after she'd been missing, I received a telephone call from the charge nurse in the ward saying: "Can I speak to Roz please?" I said: "Why are you asking to speak to Roz, you know she's missing?" She said: "Well if she should turn up would you please tell her that we have discharged her in her absence because she's broken her contract?" So I said: "Well if she turns up I will tell her." And then on Saturday at about 6.30 a.m. the police came to the door to tell me they'd found her body hanging in a cupboard off one of the bathrooms on the ward. So she'd been hanging there for three days before they found her. But I rang up the ward subsequently and spoke to the same charge nurse, who had said she had discharged her in her absence, and I said: "Do you realise when you were discharging Roz she was lying dead only a few yards away from you?"

WAITE
The hospital then launched its own inquiry into the circumstances surrounding Roz's death. We've seen a copy of that report and much of it makes for disturbing reading. For one thing it confirms that medical staff made repeated attempts to chase up the psychiatrist's review of whether Roz would be better off in the psychiatric ward and that:

> **REPORT**
> The delay may have contributed to Roz's feelings of having been rejected by mental health staff.

The report also highlights what it calls the misinformation relating to Roz's first suicide attempt and the apparent failure of communication between medical and psychiatric staff. The fact that Roz had locked herself in a bathroom, away from the ward, and tried to hang herself wasn't passed on to the nurse who carried out her suicide risk assessment. This assessment is in the form of a tick box questionnaire which rates risk on a numerical scale, from 0 to 72, depending on the answers given. So, for instance, in Roz's case the box next to the question asking:

> **QUESTIONNAIRE**
> Has the patient made a previous attempt on their life?

The answer was 'yes', a score of 12. But in the box next to the question:

> Did they use a violent method, i.e. drowning, hanging or shooting?

The nurse ticked 'no'. If the 'yes' box had been ticked Roz's score would have put her in the moderate risk category rather than the low one. Despite all this the hospital's inquiry concluded that:

> **INQUIRY**
> Staff appeared to have acted within the existing policies and procedures.

It did though recommend a number of changes to those procedures including better communication between medical and psychiatric staff and ensuring that psychiatrists, rather than nurses, carry out suicide risk assessments. But her mother, Gitti, remains convinced that on top of the so-called procedural failures in the immediate run-up to Roz's death there was a more fundamental problem with the quality of care she was getting through the existing system for treating young adults with eating disorders.

GITTI DUNHAM
When it comes to adults it seems to be that the main thing is as long as you're given the right medication they've done their duty. May be other people have different experience but my impression was that from the moment she was transferred at the age of 18 to adult psychiatry she was a lost cause.

ROBINSON
Gitti Dunham, mother of Roz, ending that report by John Waite.

Well listening to her account at the Department of Health was Jacqui Smith, the health minister, with responsibility for mental health services. Minister, in the media we're often accused of concentrating on extraordinary cases but I should say that we chose Roz Dunham's story, not because it's exceptional, but in fact because it is typical of what is happening to many anorexics. Was there anything in her story that surprised you very much?

SMITH
Well firstly I mean clearly this is a tragic story and I send my condolences to the family and it does highlight a challenge that I think we do have in mental health services and that is to ensure that we have quality for children and adolescents and we have quality for adults and we deal with some of those transition issues that I think were rightly raised and those are all things that we are currently working on.

ROBINSON
You heard Roz's mother, Gitti, say that she believes and her daughter believed that the system eventually gave up on her. Now it is very complicated to treat these conditions - it's labour intensive, it's professionally very draining - do you think there's any sense in which the system gives up or even has to give up at some point?

SMITH
Well I don't believe it does and I don't believe it should. I mean I certainly understand that for many people with eating disorders this is something where they will need health support, psychiatric and other support, over a lengthy period of time and I know that that was the case with Roz. What's important is that we make sure that whether people come into the system through the child and adolescent mental health services, where we've already seen a significant development in services but we've got a very strong target for increasing those services more over the next three years, or whether or not they come in as adults, or, as I suggested before, whether they go through that transition that I know is problematic and where we've already put responsibility on to adult mental health services to ensure that in every locality they have clear agreements about the ages and the arrangements for transferring people between young people's mental health services and older people's mental health services, that in all of those areas that we ensure that there is progress.

ROBINSON
You've talked about being aware of the problems and what your hopes are for the service. What exactly is happening because you talked also about children, adolescents, mental health services and yet giving evidence to the Commons health select committee the charity Young Minds said that the phrase itself is completely misleading because in the main these services simply do not exist?

SMITH
Well firstly, of course, we need extra resources, that's why we've already devoted £105 million over the last three years. It's why in the next three years there is a clear target on local health services to use the additional money we're making available to grow those by 10 per cent each year. It's why we've also, in terms of the mental health national service framework for adults, made clear that there need to be these local arrangements for transition between younger people's mental health services and adults, it's why we've asked the National Institute for Clinical Excellence to undertake work, to produce a guideline on how we can ensure better treatment for people with eating disorders. And it's why the national clinical director for mental health services, Professor Louis Appleby, is also carrying out a review of how we commission the very specialised services that those who are at the most serious stages of eating disorders need and how we can ensure we get a more coherent coverage across the country.

ROBINSON
Of course there's never enough money, I know that, and these discussions about funding can become very sterile and pointless. However, the £140 million that you have mentioned, if we could put that in context for a moment, the budget for the health service in England is £53.5 billion - it is a drop in the ocean.

SMITH
Well firstly the £140 million is actually for local authorities contribution ...

ROBINSON
Yes I was going to come on to that.

SMITH
On top of that ...

ROBINSON
That £140 million which keeps being talked about is actually going to local authorities, most of it is expected to be spent on children in care.

SMITH
Well I didn't - that isn't true actually and I didn't mention £140 million, what I mentioned was the £105 million that had already been spent on child and adolescent mental health services.

ROBINSON
Yes over the past three years - the figure which is promised for the next three years is £140 million.

SMITH
No what's promised is £140 million for local authorities in addition to that there is money in the significant increases and allocations to health services and to clear targets in our performance and planning framework that we published last autumn, about how that needs to be used to expand child and adolescent mental health services ...

ROBINSON
How much of the money do you expect ...

SMITH
... and in the ...

ROBINSON

.. will go ...

SMITH
...children's national service framework, which will set standards for those services, we will set down what we think those services should look like and how they should be growing and improving.

ROBINSON
How much do you think ought to be spent, will be spent, on services for people with eating disorders and on services for young people who are mentally ill?

SMITH
Well what we've said in the planning and performance framework and what we will monitor local health bodies on is a 10 per cent increase year-on-year over the next three years, measured in terms of patients seen or in terms of staff increases. Now there will be a difference in different local areas about how they achieve that 10 per cent increase because we know, for example, with relation to eating disorders that there are some parts of the country that are better served than others. So it is important that there is - that local priorities can be taken into consideration. But we expect to see that growth and we're investing in that growth as well.

ROBINSON
So you're expecting to see a 10 per cent rise in the amount of money allocated by local health trusts to child and adolescent mental health services and to eating disorders?

SMITH
Well more importantly what we're expecting to see is a 10 per cent increase in the results and I think that that's what's important.

ROBINSON
How can you separate the two - you can't give people targets and then not fund them to meet them surely?

SMITH
Well we are funding them and we're also being clear that it's not just about how much money goes in it's about what comes out at the end in terms of better services, more staff, more beds where those are necessary, more effective and joined up and coordinated services. And as I've already said, and as you in fact has already said, it isn't either just about money it's also about how we make sure that we commission effectively, how we deal those transition issues between young people's services and adult services, how we ensure, through the National Institute of Clinical Excellence, that we all understand what is good practice when we're treating people with eating disorders and we ensure that that is more widely spread across the country than it is at the moment.

ROBINSON
Some of the very basic injustices, the way, for example, services are rationed, in some areas, we heard in John's report, you're not referred to the adolescent psychiatric services unless you're in full-time education, why don't you, as the minister, do something about that? You could do something about that with a stroke of the pen.

SMITH
Well what we're doing is we're ensuring, as we develop the children's national service framework, that we do set national standards for what we expect to see from child and adolescent mental health services. Now you suggest there are things I can do with the stroke of a pen, actually of course what we need is a health service that looks at the particular needs in its local areas, uses the extra investment going into the system, takes on board that we have made a specific priority of developing

child and adolescent mental health services and ensures that they are delivering services that make sense at a local level.

ROBINSON
Jacqui Smith thank you.

Dr Paul Robinson is here in the studio, he's a consultant psychiatrist and he chairs the eating disorders special interest group at the Royal College of Psychiatrists. That was the view from the Department of Health, how is it for patients with eating disorders and their families approaching the NHS?

PAUL ROBINSON
Well their experience is that the services are extremely patchy across the country. I wouldn't call it a post code lottery but there are some places - most of Wales, most of Scotland, Northern Ireland, the South West peninsular - where there's virtually no access to specialist eating disorder services. And I think rather than band the figures about expenditure I think it might be really helpful to work out do we really want specialists in eating disorders accessible to local populations? Our view, at the Royal College of Psychiatrists, is that somebody who knows about the problem is better placed to deal with it than someone who doesn't have much experience in it, we think that's self-evident and reasonable. And so all we're asking for is for specialists in eating disorders - and they have to have the specialism in the medical care and the medical complications of eating disorders as well as the psychological and psychiatric problems, as well as the family and social problems, so it's quite an unusual animal we're talking about. We want someone like that - and it's most likely to be a psychiatrist in our view but we know there are services run by psychologists and nurses, excellent services - as long as it's someone with enough expertise accessible to the local population in all areas of the country. I think that's the problem. So if you get an eating disorder and you live in Penzance you're going to have to get on a train or be put on a train or in an ambulance and perhaps travel to London for treatment.

ROBINSON
The point that the minister raised - that this - the matter of how best to treat eating disorders has now gone to NICE for national guidelines - do we need to do that or do we already have some of the answers?

PAUL ROBINSON
Oh no the - I'm very in favour of the NICE committee and I think I very much look forward to their views. And I hope that they will give a view on this. I must say if they said it's alright for generalists to treat eating disorders I would disagree with them and I'd want to oppose that.

ROBINSON
We heard Peter Webster from the Maudsley Hospital saying that if you can get this condition within the first year your chances of curing it rise hugely - why?

PAUL ROBINSON
I think it's about the fine threads that link you to your social network, that if you've had an eating disorder for five years most of your life is the eating disorder, it's the obsession with food, the depression, the fighting with family, fighting with treatment services. And that becomes your whole life and it becomes much more difficult to get back, I think, to what was your life before. Whereas if you catch it within six to nine months it's much easier to - it's not that easy but it's much easier, much more possible to link someone up with their previous life.

ROBINSON

Richard Brook is from the mental health charity MIND, we heard in John Waite's report about the differences in culture between the child and adult mental health services, how does that difference in culture affect families?

BROOK
Well I think it affects families enormously and I think you can't help but feel, I suppose, compassion but both also a feeling of anger and frustration as you hear that story and also hear the minister's comments really because we know that the actual reality for people on the ground is extremely different to the strategy and the targets that we've heard talk about. At MIND and many other places that deal with mental health issues on a day-to-day basis we hear everyday of the difference between the reality of people's experiences and the strategic targets, there's a national suicide strategy, there's a dual diagnosis strategy to deal with alcohol and mental health problems and yet the reality for people on the ground, working in the service and people experiencing as service users, families and carers that it's not the same.

ROBINSON
Is it just a question of policy taking time to feed through?

BROOK
I don't think so at all, I think there's a huge gap between the sort of concept of setting national strategies and making a differences on the ground for people and we've had - this strategy's been running for three years, we're talking about another three years and yet the reality for people is in very few places has been real significant change. I hear it everyday as I go round the country. And I think it's about time that we tried to join up the local initiatives that we need to see, along with the national strategy before this money gets dissipated, it's lost, it isn't focused on where it's needed.

ROBINSON
Dr Robinson we heard how Roz's family felt excluded when she moved from a service which looked at the family and did therapy with the family, perhaps in some cases to one which concentrates the adult psychiatric services concentrate on the individual and look to drugs as the answer to their problems very often, in the inquiry report into Roz Dunham's death, it's emerged she was taking four separate tranquillisers and the psychiatrist cut two of them because he thought they might be doing more harm than good. How can you make two such different services dovetail?

PAUL ROBINSON
Well I think the description of adult services is a little caricatured. It's increasingly, thanks to the research that's gone on, adult services are taking account of families and there's one thing I want to say which is that at the age of 18 you have the right to exclude your family from your treatment through confidentiality. So if a patient of 18 says I don't want my family involved then you're not allowed to contact them and that does cause extreme upset to parents who've looked after their child with an eating disorder up to the age of 18 and suddenly they're told well you're not involved anymore.

ROBINSON
What do you do about it where you work?

PAUL ROBINSON
Well I think it's difficult. Mostly patients will allow contact with their families and at the Royal Free we regard family therapy as - and family support as an absolutely essential part of treatment of an eating disorder. The question about the dovetailing of the two services - at the Royal Free we have child psychiatric services dealing with eating disorders and our own adult service and generally a patient will be referred to us in good time, we may see the patient together with the child psychiatrists and try and make the transition over a year or so.

ROBINSON
But what age do you do it - is there a cut off age?

PAUL ROBINSON
It is variable, we will accept patients in the adult service from the age of 16 if the child psychiatrists want us to do so. So in other words we don't have a sort of strict cut off point. We think - I think anyway 16 to 18 is not a good time to change, certainly 18 I don't think is a good time to change services from child to adult. And I think there is an argument, in my view, and this is a personal view, for a young person's service from say 14 to 25, something like that, because so many of the mental illnesses start in that age group and the treatment is only just getting going by the time they change into adult services and unfortunately we're bound, at the moment, by the services which are very strictly delineated as adult or child.

ROBINSON
Well I wanted to bring in Debbie now, who has had, is it, anorexia?

DEBBIE
Yes it is.

ROBINSON
And you're now in your 30s, so you've had anorexia for most of your adult life?

DEBBIE
Yes.

ROBINSON
What do you think was the cause of your condition, is the cause of it?

DEBBIE
That's something I'm still working on at the moment really. But it's probably like an accumulation of sort of several things really.

ROBINSON
Like?

DEBBIE
Probably being very sensitive to sort of the environment around me, the perfectionist - like we were speaking about with Roz's story.

ROBINSON
What's been your experience of trying to get treatment through the NHS?

DEBBIE
It has been very difficult. I mean when I was - when I was younger I was referred to the child services and did have a stay in an adolescent unit but as time has gone on it has been more difficult to actually access help - more specialist help with sort of treatment being more on a general basis really.

ROBINSON
I know that you've had some success in overcoming your illness and perhaps I should say you certainly look very well today through staying at somewhere called Newmarket House, which is a clinic in Norwich and Penny Bailey, who founded that service, is here. What on earth do you do when it works?

BAILEY
I think it's very easy to get hung up on treating the symptoms of this illness without actually looking at the underlying causes.

ROBINSON
Except if people are going to starve themselves to death, as we heard in John's report some people do, you have to find a way to make them eat don't you?

BAILEY
Oh indeed, there's absolutely no recovery without weight gain. But at Newmarket House we don't talk food, we don't talk calories, we don't talk target weights - we take care of all that, weight gain is essential and we totally respect that but there's a great deal of emphasis of attacking the underlying causes. And I think also actually what is absolutely vital that we do is that we have a planned gradual discharge - there's no point whatsoever in taking patients in for a long period of time and then just discharging them without any sort of follow up, terribly, terribly important that they should be helped to become independent and get back to living in the community.

ROBINSON
Debbie what was it about the regime that you felt helped you?

DEBBIE
I think it's like Penny was saying - it's a more holistic approach than I've experienced in the past and the gradual sort of transition with the halfway house giving you back more independence and not just sort of once you've got to a target weight letting you go back into the community again to fend for yourself.

ROBINSON
Dr Robinson the inquiry report in the aftermath of Roz Dunham's death said that she responded well when staff simply spoke to her and she had a chance to talk to them. Again and again patients on mental wards will tell you that staff are unwilling to engage with them - do you think that the staff themselves eventually suffer compassion fatigue?

PAUL ROBINSON
I think if you think about the position that adult psychiatric services are in at the moment, over the past 10 years or maybe a little bit longer there have been a series of disasters that have occurred where adult psychiatric patients have hurt members of the public or committed suicide - all sorts of things like that - and there have been a succession of government paper exalting psychiatric services to make sure that people are safe - they don't commit suicide and to make sure that they don't hurt other people. And this has resulted in I would say a deluge of paperwork which is affecting adult psychiatric services and this is why the adult services are so focused on these aspects, both in-patient services and community services. Which is why I say I think they need help in dealing with a specialist area like eating disorders which is not part of their usual treatment.

BROOK
Absolutely and I think Paul is absolutely right to talk about that. We need to see a change in adult services and the culture and how people help and how people are helped through a whole range of ways, not just through medication and being contained almost within wards. And we also need to see a range of services and undoubtedly there are some areas that are Cinderella services, even within the Cinderella service - mental health services - and eating disorders is one of those and we need to see a much more comprehensive approach and a much more client based, users based, focused approach which actually does things. I mean some of the things we heard about on your report was very much about talking to people, engaging people, making people feel confident in the service that

they're receiving and I think that's absolutely key as I'm sure others if they use services like that would absolutely say and testify to.

BAILEY
May I just say here that we take patients - we set up independently but most of our patients, 98 per cent, are NHS funded and they come from the South West, the North West, Scotland, Ireland - it's an absurd situation for these people and makes it much more difficult doing work with families when they have to make such huge journeys.

ROBINSON
It's a very difficult group of people isn't it? You heard Roz's mum saying that she spent three hours trying to feed her a carton of ice cream, when people are so hungry for attention, which was something else that came out in some of the professional judgements on Roz when she was in hospital, that she just wanted attention, how do you find people with enough to give that group of patients?

BAILEY
We have a staff of 65 people for looking after 16 beds. It is hugely labour intensive. Most of the people who joined us when we set up seven years ago are still with us. I mean are very, very dedicated, very committed - it's a very, very rewarding job. But they have to be trained specially in this particular field, it's a very specialist field.

ROBINSON
We're almost out of time now, I just want to end by asking you briefly if each of you, if you would, tell us what you think is the lesson from Roz's death, Paul Robinson?

PAUL ROBINSON
Well firstly how serious eating disorders can be, I think they're often trivialised. Secondly, the importance of managing the transition between adolescent services and adult services. Mainly, however, I think the need for local expertise in eating disorders wherever you are in the country.

ROBINSON
Debbie?

DEBBIE
I think it's just the need for like the gentleman said about having the specialist units with the specialist trained care and taking the holistic approach, not just looking at the weight and the BMIs but actually at the mental state as well.

ROBINSON
BMIs - body ...?

DEBBIE
Body mass index.

ROBINSON
Penny Bailey.

BAILEY
Treatment is extremely expensive, I would like to see very much more emphasis placed on educating staff in schools to recognise the symptoms at a much earlier stage because it almost always the link between these patients is the perfectionism and I think teachers must be aware of the stress that they're placing on their pupils.

ROBINSON
Richard Brook?

BROOK
I think for me it's recognising the reality of Roz's story and what we need to see is a change locally, so that services are there that prevent Roz's story being repeated, which it certainly is still very commonly in our country today.

ROBINSON
We have to bring our discussion to a close there. My thanks to Jacqui Smith, the health minister, Dr Paul Robinson from the Royal College of Psychiatrists, Richard Brook from MIND, Penny Bailey, founder of Newmarket House and Debbie, who has been treated there, many thanks to you all. If you want more information about eating disorders you can call our helpline: 0800 044 044. If you want to hear the programme again you can log on to our website: www.bbc.co.uk/radio4/youandyours and you can e-mail us with your thoughts at the same address. John.

WAITE
That's it for today Winifred. Tomorrow the railways with passengers waiting longer for trains and overcrowding at its worse for many years, recent announcements have delivered yet more bad news with cuts to both services and improvement projects. Well tomorrow we'll be speaking the man whose job it is to shape the future of the network, he's Richard Bowker, chair of the Strategic Rail Authority. And we're very keen to hear your views on the state of our railways and any questions that you want answered. You can call us on 0800 044 044 or you can e-mail us through our website, as Winifred said, at bbc.co.uk/radio4/youandyours but remember if you do please to leave us your phone number so that we can call you back. See you tomorrow 4 minutes past 12.