

P-04-408 Child and Adolescent Eating Disorder Service – Correspondence from the Petitioner to the Committee, 17.05.17

Dear Mr Hedges

Thank you so much for considering the petition that I submitted some 5 years ago, and which the last committee felt was important to keep on the agenda.

I am extremely grateful to the now Minister Health Wellbeing and Sport, Gethin Vaughan, for taking time to respond to your letter and for considering this important topic.

I wonder if a rough outline as to how this petition came about, and also what has been achieved over the years might be of some help?

Over the years I have kept my personal experience to the minimum, deciding that the X factor sob story is not my style. There is one though!

In 2009 our then 15 year old daughter was diagnosed with anorexia nervosa. A high achieving A grade student had the bottom of her world pulled out from under her, as did we as a family. We took her to the GP within weeks of realising something was drastically wrong. All research indicated that early, specialised intervention was, and remains, key to recovery. (Neural pathways are laid down in mental illness, in children this is highly malleable at the early stages of the illness... The sooner these thought patterns are realigned, the quicker the recovery. The brains of those affected by malnutrition are not in a fit state to access help for themselves, thus families become central to the treatment, whilst refeeding is used to promote full nutrition alongside therapy.

<http://www.maudsleyparents.org/whatismaudsley.html>)

Unfortunately, the specialist service was not available in CAMHS at that time in our area. Our daughter was told she was 'not ill enough' to warrant a referral to the expert in North Wales, Dr Glaze. The long and short of our story is that our daughter is still unwell with anorexia. We have taken her privately now (at great cost to us, but that has been our choice), and she is in a strong recovery at present. She is about to graduate from Durham Uni having read Anthropology.

I do not have a bone to pick, I merely saw there was a need in CAMHS in Wales, to have investment.

The Eating Disorder Framework for Wales (2009), was put together for the benefit of adults with eating disorders. A million pounds, ring fenced and annual, was put in place for adult teams.

The thought then was that CAMHS could manage EDs in their general case load, and indeed did. Research and understanding has changed over the years, and the magnifying glass of early intervention has swung back to CAMHS.

The £250,000 for South Wales, given in 2013 by Mr Drakeford, was a nod to this very fact.

I intend for the now Minister for Health and Sport to give the remaining £750,000 that is outstanding for the rest of Wales in alignment to that which is given for adult services.

This, as I have said many times, enhances a better outcome for health boards expenditure on people who suffer for longer than is necessary.

To treat early, with effective evidence based treatment in an effective specialist way, causes the person with the illness to recover quickly!

Out of adversity comes strength, and I decided that I needed to understand these illnesses and so be able to help our daughter, and indeed many other families.

My thoughts remain that I want no other family to go through what we have, knowing now what I do: these illnesses can be recovered from. They are to all intents and purposes 'curable', with effective treatment.

I have been fortunate enough to be asked to participate in the Cross Party Group for EDs as well as being a carer representative on the Eating Disorder committees, Transition Sub committee and Research Development Group for eating disorders here in Wales.

I have over these past 7 years also been on the EDIC (Eating Disorder International Committee) planning committee, I am a managing trustee for Charlotte's Helix, and a member of the FEAST (Families Empowered and Supported in treatment of Eating disorders, www.feast-ed.org) task force for the UK. I am also an individual rep for PAVO.

I was also asked by Public Health Wales to represent carers by giving talks in the refresh of the framework last year.

There is no choice to eating disorders, much as there is no choice to appendicitis or a broken leg, heart disease, an autoimmune disease or breast cancer. None of which would be labelled as a disease of 'silly girls', these are serious, destructive physical illnesses as anorexia or bulimia are mental illnesses.

Eating disorders, especially anorexia, have the highest mortality rate of any mental illness, and this remains to this day.

Some people are genetically predisposed, with personality traits that may or may not cause the 'perfect storm' to occur, with environmental and social triggers being on the very edge of the loaded gun as to why some people succumb to an eating disorder.

Research into mental illness is beginning to uncover what is going on in the neurobiology of the people affected, as well as the genetics.

<http://www.psychiatrictimes.com/special-reports/neurobiology-eating-disorders-clinical-implications>. (www.charlotteshelix.net) Weight loss is merely a symptom of the illness, somewhat like a rash in chicken pox...shingles may or may not occur later in life with the right environment in place for an underlying illness to rear its head in another form.

As you may know the petition has given the last Health Minister, Mark Drakeford a leaping block to investment into CAMHS eating disorder services, which has brought much needed funds to create a new service based in the South of Wales. As Mr Vaughan rightly points out this service has provided training, both remotely and in conference style, to many CAMHS teams across Wales.

Dr Davies is a skilled and specialised psychiatrist in the area of Eating Disorders and brings a wealth of expertise and also the Maudlsey Method, as a recovery model, for best evidence based treatment for young people with Eating Disorders (ED).

I applaud her and her team.

However, this team, and indeed Dr Davies are part time. To be able to provide and facilitate as much training as possible, I do think that further investment, specifically in that team thus enabling expansion, would be prudent.

Training of all CAMHS teams across Wales takes time, and indeed the complexity of eating disorders means that teams must keep training and thus become embedded in the evidence base and practice with these specific illnesses.

To enable this I wonder if the minister would consider investing specifically in all Health Boards to make 'virtual teams' more robust, and within that provide dedicated staff for eating disorders?

The virtual teams that are in place, both in the north and south of the country are making some inroads into the training and diagnosis of patients.

The current standing, as I understand it, is that existing staff carve out some time from their job plans to undertake ED work. This causes extra strain and less time investment into the already heavy case loads.

Dr Glaze in North Wales (NWAS, North Wales Adolescent Services) runs a multidisciplinary team (MDT) specifically set up for the early intervention in eating disorder treatment, named aptly SPEED. It is centrally and locally delivered, and comprises of paediatric and psychiatric consultants, psychologists, family therapist, dietetics and is underpinned by the Maudsley method, which as Mr Vaughan rightly realises is the best practice for treatment.

The very fact this team is early intervention for referrals from across North Wales and North Powys is exemplary.

This has been set up with little funding from central government and needs more investment. The referral rates are massive and not enough time can be given to it, as there are other needs in CAMHS for Dr Glaze to turn his hand to.

He has an empty ward, which if more funding were given, could potentially be opened to the SPEED team and an outpatient setting specifically for eating disorders.

The south of Wales would benefit greatly from paediatric expertise and influence. Perhaps, as in North Wales a dedicated paediatrician to ensure sufficient and combined expertise.

The 'middle' of Wales needs some attention, as there is a population who do live in these areas!!!

To underpin all of these thoughts we should return to the Framework for eating disorders, which as Mr Vaughan mentioned, was refreshed last year by Public Health Wales.

In Dr Khesh's summary of findings from the refresh he quoted the Together for Children and Young People initiative:

"Previous reviews of specialist CAMHS in Wales have identified that the service is under more pressure than ever before, and inspire of additional investment and staffing, does not have the capacity to meet demand (PWH 2011)"

He goes on to point out: "Over the past 4 years it is reported that there has been over 100% increase in referrals to CAMHS, this adds to waiting times of children needing specialist services."

He highlights that there are some hotspots (my words) that need looking at, namely Powys and North Wales which are repeatedly flagged during the process by carers and service users.

Now, these findings clearly cover adult services as well, especially in North Wales, however, it remains a problem in Powys especially in the delivery of CAMHS services for eating disorders.

The NICE guidelines for EDs is being released imminently, and at the time of writing this, have not as yet been released. They will need to be looked at as to how to go forward with the refresh of the framework. Dr Khesh in the Public Health refresh document also suggests a re writing of the framework.<http://gov.wales/docs/dhss/publications/160824eating-disorderen.pdf>

I am aware that monies have been negotiated for all eating disorder services across Wales to the sum of £500,000 annually. I am also aware of the thoughts as to what this will be spent on.

The holes that will inevitably be plugged with this money, will not be at the grass roots of early intervention, but will be used more broadly.

As a summary then, I still stand by the fact that the Welsh Government have a duty to provide more funding specifically for the Early intervention within CAMHS for eating disorder treatment. This needs to be specifically for staffing and the rolling out of the already seen to be improving outcome services.

An injection into already functioning, and seen to be improving outcome measure services provided both by Dr Glaze and Dr Davies, plus an injection to all health boards specifically for ED services in CAMHS potentially increasing the VC service, thus enabling staff to concentrate their efforts into the treatment of children and adolescents at the onset of these illnesses.

Thank you again for taking the time to read and understand the thoughts behind this petition.

Helen Missen