22nd March 2013

Dear Mr Powell

Re: Ministerial Response to Petition by Helen Missen

Many thanks for giving me the opportunity to comment on Paul Haynes response to Ms Missen dated 25th September 2012, and to comment on whether or not support services for children and adolescents with eating disorders are sufficient or not. I will start with comments on Paul Haynes response.

Commentary on Response to Petition

I would like to start by saying that I agree that eating disorder services have formed a core part of the work of CAMHS services for as long as anyone can remember, but it is not true to say that many adult eating disorder service models are based on good practice models originally developed within CAMHS. I suspect that Mr Haynes is referring to the use of a tiered model here which, whilst beneficial, is only a small part of an appropriate set of services for adolescents with eating problems. Secondly, whilst it is true that the specialist adult eating disorder teams across Wales do occasionally receive severe eating disorder cases from CAMHS, at the transitional age of 18, the vast majority are transitioned to regular Adult CMHT services, or back to primary care. So it is not really true to claim that the adult Tier-3 specialist eating disorder teams support young people in transition between adult and CAMHS services without considerable clarification.

Clearly the £42 investment in Ty Litchard and the North Wales Adolescent Service (NWAS) has been a welcome addition to services for eating disordered young people in need of inpatient treatment. The North Wales Adolescent Service particularly prides itself on the work it does with eating disordered patients but the detail provided by Mr Haynes on NWAS has changed significantly in the last 18 months and it presently consists of 12 generic beds for emergency and urgent referrals. It does however have a superior and integral education unit with a social worker also based on site. There may also be inaccuracies in the description of Ty Litchard, though I am less clear on the specifics for them.

I am uncertain to what Mr Haynes is referring in the 2nd paragraph of the second page of his response where he mentions the “all-Wales Eating Disorder service”. Again I suspect he is referring to the All Wales Eating Disorder Special Interest Group (AWEDSIG). This consists of an extensive network of professionals concerned with the assessment and treatment of sufferers of eating disorders, their carers and an organizing management team. The AWEDSIG management team is Chaired by Dr Robin Glaze (Lead Clinician for the North Wales Adolescent Service) and exists to plan and implement 3 free educational meetings a year for practitioners in Wales and to lobby for, and advise on, services for eating disordered patients. The management team, and the network of

practitioners, has a mixture of professional disciplines and covers both CAMHS and Adult services with a strong B-Eat presence and joint working. It is not AWEDSIG's specific aim to create pathways for young people suffering with eating disorders nor to facilitate transitions between CAMHS and adult services. AWEDSIG did, however offer much support and advice to Dr Peter Boyle who authored the Eating Disorders Framework for Wales published in June 2009.

The vast majority of adolescent patients with eating disorders requiring inpatient treatment would indeed be managed satisfactorily in the two Welsh adolescent inpatient units. Services for adults in generic adult wards are highly variable and some will likely be less than satisfactory. At present a very significant number of adult patients end up having inpatient care in NHS units outside of Wales (Marlborough and the Wirral). The provision of adult eating disorder inpatient care is presently being reviewed and an options appraisal taking place as the contracts come up for renewal.

Finally, Mr Haynes makes no specific reference to the intelligent target for eating disorders which does have a clear role in the improvement of quality of provision of eating disorder care across the age range. This would have been a useful addition.

Comments on Services for Adolescents with Eating Disorders

I have given considerable thought to this issue. Services for adolescent eating disorders are arranged differently in North and South Wales so some specific comments are required for both though some more general comments are common to both. Firstly, CAMHS services suffer from many of the same issues that adult services do. Primary care may refer late which worsens prognosis, increases medical risk and complicates the task of therapeutic engagement for the receiving CAMHS (or Adult) team. So there remains an important task to ensure early referral and appropriate psychological and medical assessment in primary care. Carers often report that they have been told not to worry, it's just a phase, whilst their young person is losing weight rapidly for instance. Secondly waiting list pressures may lead to adolescent patients having to wait longer than is desirable before assessment by community CAMHS, particularly if adequate medical assessment is lacking at the point of referral. Thirdly, as with Adult Services, access to dietetics is not commonly present, and meal planning skills may be absent in many Tier-3 teams. Fourthly, the small number of eating disorder cases passing through Tier-3 CAMHS teams may well mean that the workers never get sufficiently practised at this work. Fifthly, late referral often leads to more admissions than should otherwise be required. Sixthly, I am concerned that LHBs cut down on education and training during periods of fiscal restraint, and it seems to me that regular training is an essential component to the maintenance of skills within Tier-3 CAMHS teams. Finally, carers often complain to me that they are not given satisfactory information or that there was insufficient urgency in the teams response.

Failure of implementation of the intelligent target for eating disorders by CAMHS is also, I would suggest, an important strand. The envisaged transfer of resource to designated eating disorder champions within CAMHS teams proposed by the Framework for Wales has not occurred and many CAMHS teams have yet to implement the eating disorder intelligent target, in part because of the poor base with which to start this very complex piece of work. This has yet to be reviewed by Welsh Government despite a plan to review in 2012.

On a positive note, I do think that CAMHS teams have the very real benefit of a comprehensive spread of healthcare professionals, which tends to be less present (or indeed absent) in some CMHTs. So it certainly makes sense to ensure that finance is routinely available for regular training in this setting.

Differences in Adolescent Eating Disorder Service Provision in North and South Wales

South Wales has Community Intensive Treatment Teams (CITT) teams. These are small multi-disciplinary outpatient teams that are able to see patients daily and in their homes and schools as required. Many Tier-3 outpatient CAMHS teams refer Eating Disorder Patients to CITT once an intensity of once a week contact has been reached. This breaks continuity of care, but is in other ways beneficial. They are not, however, resourced to cope fully with the current demand, and not universally present in all districts. South Wales also has a specialist eating disorder assessment clinic based at Ty Litchard. Unfortunately this is only open one morning a week (which is too little) and cannot deal with emergency presentations satisfactorily. Clearly travel is problematic given the huge distance served.

In North Wales there are no CITT teams, though a different type of intensive community support team is currently being designed and funding secured. This will have some small impact on a subset of eating disorder cases as it will increase the ability of Tier-3 teams to have contact 3 or 4 times a week and will bridge the gap between Tier-3 (community) and Tier-4 (inpatient) CAMHS services.

In addition to this response regarding the petition I would like to add that whilst raising awareness across Wales, the 'Beat Cymru' team meet and talk to many Carer's and Sufferers who are using CAMHS and Eating Disorder Services. Some of the feedback from them is as follows:-

- Parents feel that more money should be put into CAMHS specifically for Eating Disorders
- That there should be specialised staff within 'CAMHS Eating Disorder Services'.
- That there should be 'Funding in Wales for a Unit'.
- Better transition between CAMHS and Adult ED Services
- Greater awareness among GP's, it's not a fad and teenagers won't grow out of it.
- Parents whose child died of anorexia told Beat Cymru that their local GP did not diagnose correctly when it would have counted. 'Only when my daughter was admitted to the local hospital did I realise that they were not set up for such an illness, there was no urgency, little or no education amongst the doctors or staff and no specialist support, resulting in another tragic loss which we feel could have been prevented'. To this day there is only one GP in our local practice that is receptive to eating related disorders, it seems that they do not understand, are too willing to write out prescriptions for anti depressants, if they do understand, they do not have the budget or trained staff to make a difference.
- On the positive side parents and sufferers comment that they find it reassuring to have a local Beat (Cymru) presence in their community and support close to home especially as many often have to travel out of Wales for treatment.
- Parents and sufferers feel that awareness raising of Eating Disorders in their country is good, and they welcome the opportunity to get involved through sharing their experiences with others or talking to the media. In particular they feel that the more that eating disorders is talked about in Wales, greater is the possibility of reducing the existing stigma.

Summary

In summary, I am not convinced that community CAMHS services for eating disorders are sufficient and would support Ms Missen's argument for matched funding. There is a very clear need for increased training for CAMHS professionals, a more networked approach across Wales and a formal assessment of the merits and consequences of specialist CAMHS community eating disorder services. I would cautiously suggest that a working group of knowledgeable CAMHS clinicians, working regularly with eating disordered patients, be convened to look critically at the issues involved. It would also be helpful to seek advice from the All Wales Eating Disorder Special Interest Group (through the Chair, Dr Robin Glaze), and to use AWEDSIG and ourselves to review the outcome of any proposals made for practicality and relevance.

Best wishes,

Yours sincerely

Susannah Humphrey