

P-04-408 Child and Adolescent Eating Disorder Service – Supporting information from the Petitioner to the Committee, 23.09.2013

Dear Committee Members,

Thank you once again for taking this petition seriously.

1. This is, I understand, my last opportunity for input prior to the meeting on 8 October, which I shall be attending. It has been a bit of a learning curve to understand the procedures involved in dealing with a petition, and I hope that any amateur impressions in that respect will be forgiven.
To recap, I decided to initiate this petition a year ago in consequence of the experiences of my family and myself, and of the similar experiences of many families with whom I have been in touch. I did not consider it appropriate to give details of those families without their consent, but suggest that if any further research is needed before granting the petition then they should be approached in a proper manner.
2. Although I am not myself a professional (beyond being a qualified nurse employed in BCUHB) I feel I am no longer an amateur in relation to the whole field of eating disorders (ED).

Since my daughter developed an ED some 4 years ago, I have familiarized myself with a vast quantity of information and with a large number of relevant people, not only in Wales but in UK and internationally. Some of these have been leading specialists in treatment of EDs, some non-specialist professionals in the mental health services, some support groups such as BEAT. I do now feel that I probably have more knowledge in the field of EDs, particularly in relation to treatment and prognosis for minors, than many of those professionals who deal with first referrals.

3. A year ago I embarked on the petition process, having seen and experienced the disparity of funding for Specialist EDs in the Child and Adolescent Mental Health Services (CAMHS) in comparison to Adult ED services (AEDS) here in Wales. I stand by my original call for equal, if not more funding for specialist eating disorder services in Wales within CAMHS.
4. In the past four years I have been encouraged by the stance of the Welsh government in the addressing of ED services. Wales is well equipped with documents, groups of working parties and well meaning professionals. The Welsh Framework for EDs (2009) and the 1000 lives initiative launched on the 1st March 2012 are steadfast in their approach to 'improving care'; but it is a matter of grave concern that it seems to take so long for progress to be made. It appears that the "intelligent targets" have not been implemented uniformly across

Wales, and that they do not go far enough in providing specialist help at stages prior to Tier 3. Such help needs to be cross-disciplinary, including specialist dieticians as well as ED specialists.

5. The petition calls for funding, stemming from the need for early intervention in the treatment of EDs. This is backed up by both the Welsh Framework for EDs and the 1000 lives. Both stipulate it is fundamental to good, evidence based treatment. It remains the simple fact: the majority of EDs begin in childhood and early adolescence, a fact that cannot be changed, a fact that all professionals in this field agree with, a fact that I have quoted, as have the above mentioned gold standard documents that underpin the Welsh stance on EDs.
6. At present, the Welsh CAMHS system is full of gaping holes in the treatment of eating disorders. There is both disparity and discrepancy of care across Wales, evidence of which the Cross Party Group and Beat, alongside Dr Robin Glaze, Dr Menna Jones and others have reported.
7. I understand the need for an evidence based approach in all areas within the NHS and I do believe that the evidence should be gathered from all sources, including actual service users. I believe that families of patients with EDs should be approached, preferably by an independent body.. Their stories should be heard. At present, I have families approaching me, at their wits end. In this day and age, families are already under enormous stress, strain and financial pressure. Adding the complications and difficulties of an ED to a family unit increases stress to unbearable levels, especially when the treatment provided is inadequate, unhelpful and not evidence based or concurrent with latest protocols. I do believe that one of the next steps forward should be to include the service users, the clients, the 'carers and sufferers' as they are labelled.
8. Junior Marsipan is a wonderful document and to be applauded. However, with earlier intervention, appropriate training for CAMHS teams in the latest treatment protocols, and arming families with the right tools to treat this disorder at home, with the back-up of the Tier 1 & 2 clinical teams including cross-disciplinary specialists as above, many more children will be 'saved' long before both Junior Marsipan and in patient treatment is needed.

I am fully committed to Wales becoming a leader in the UK as far as the treatment of EDs go and I am thrilled that the AEDS tier 3 service has been created. It is invaluable.

9. However, I return to early intervention. CAMHS, if provided with specialist expertise at tier 2 level would be better equipped and the overall service would be more effective. The need for crisis admissions to Inpatient Units and the cost to the NHS of emergency admissions would be reduced, probably greatly, if early intervention, training of CAMHS teams, better support for parents at home and

training and help for parents were an integral part of Tier 1 & 2 care for families of patients with an ED.

10. At present, CAMHS “leads” with simply a special interest, who through no fault of their own, may lack knowledge and experience and expertise of these highly complex illnesses, may and do make mistakes and mis-judgements, which often result in emergency admissions to both hospitals and inpatient facilities. Needless to say, this results in even more stress and sometimes in devastation for the sufferers and their families.

It is also very important that non-specialist staff in CAMHS are better trained and educated in dealing with the urgencies involved in earlier stages of EDs, and in understanding the multi-disciplinary needs and the comorbidity issues, such as low mood, family problems and educational disruption. Virtual training and conferencing could perhaps play a valuable part.

11. 1000 lives calls for training of tier 1 and 2 by tier 3 specialists. I would suggest that the specialists should be in tier 2 thus bringing earlier appropriate intervention into the equation.

A specialist for EDs within every Local Health Board is one of the recommendations made by the Framework for Eating Disorders. That is still too far removed from the patient, but even that is not in place throughout Wales. 2009 is now 4 years ago!

12. I agree some children and adolescents presenting at Tiers 1 and 2 may not in any event progress to a chronic ED, but this is a rarity, rather than the norm. The point is that many who do progress to a chronic disorder (with consequent very expensive long-term funding implications) might at much lesser cost have been spared a lifetime of entrenchment in their illness, if they had only had early intervention by specialists with expertise and experience. Anorexia Nervosa still has the highest mortality rate of any mental illness.

Leaving aside the emotional and human cost (though of course it is a perfectly valid if not overwhelming factor), I remain convinced that the risk of putting extra funding into early intervention is one worth taking in funding terms, in view of the likely savings on long term treatment, even though it may not be possible to forecast this result precisely. Please do not use pure figures as an excuse for inaction.

Helen Missen