



HEALTH AND SOCIAL SERVICES COUNCILS'

RESPONSE

TO

REVIEW OF EATING DISORDERS SERVICE

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REVIEW OF EATING DISORDERS SERVICES

Response to the consultation document

1. INTRODUCTION

This response to the consultation document is a combined response from Northern Ireland's 4 Health and Social Services Councils. The Councils are independent consumer organisations which were established in 1991 to represent the views and opinions of the general public in all areas of health and social services.

The Councils welcome the opportunity to comment on the Review of Eating Disorder Services consultation paper and commend the project team for recognising the urgent need for service development. While we offer a range of comments on specific aspects of the consultation paper our overall view is the proposals to develop eating disorder services within Northern Ireland are to be welcomed. The prevalence of eating disorders has increased in the recent times and these disorders, as the document states, "compared to other psychiatric conditions/syndromes, have a particularly high level of mortality."

As organisations charged with the task of representing service users we are concerned at the lack of any indication that service users and carers have been involved in the review process or in the drafting of this document. The report provides no information on the membership of the Project team nor does it indicate that users and carers were consulted about their experiences so as to inform the proposals contained within this document.

2. BACKGROUND

Paragraph 2.1 of the consultation document states that “*usually the term eating disorder is used to describe anorexia nervosa or bulimia nervosa although it may include other disorders such as obesity when used in the wider context.*” However the document goes on to discuss the issues associated with anorexia nervosa and bulimia nervosa alone. As such it is not clear whether the proposals for specialised services will focus only on these two eating disorders or whether they will also address binge eating. Binge eating disorder has only recently been recognised as a separate eating disorder but binge eaters share the same underlying psychological problems of low self-esteem and lack of self-confidence. Where binge eating results in obesity there are significantly increased risks to the physical health of the patient. It is important in the development of specialist eating disorder services in Northern Ireland that binge eating is recognised as an eating disorder and treatment provided to this group of people.

3. ASSESSMENT OF LOCAL NEED

As stated in paragraph 3.1, the Councils accept that there is little epidemiological type data available with respect to eating disorder incidence and prevalence in Northern Ireland. As such it is justifiable to use indicative levels and trends reported within the UK in general. The Councils do not consider hospital admission data as a useful proxy because, as the report details they are more likely to reflect availability of services rather than need.

Monitoring of the incidence and prevalence of eating disorders is an important task which should be undertaken once specialist services are established.

Local voluntary groups which provide a helpline service, self-help support groups or drop in facilities for people with eating disorders and their carers¹ can also provide data for use in the assessment of local need. While this type of information may not include accurate figures on prevalence and incidence rates, these groups are well placed to advise on the range of services required. In the months following their *Eating Disorders and Mental Wellbeing Conference*, ADAPT which is a voluntary organisation based in Lurgan, detailed that they received 46 calls to their helpline and 84 calls for information about eating disorders. They also received 40 referrals from GPs and 15 from the local Trust².

4. SERVICES ELSEWHERE

The Councils support the approach of looking at examples of services elsewhere when developing services in Northern Ireland and there is a wide range of models, including the two examples quoted in the consultation, to learn from. The Marino Therapy Centre³ in Dublin is another model which may be useful in the development of services in Northern Ireland.

It is important to evaluate the outcomes of services elsewhere when choosing models for service development within Northern Ireland. A full range of outcomes should be assessed including: - the individual's ability to return to education/work, self-esteem, maintenance of relationships

¹ ADAPT, Derry Well Women and Eating Disorders Association

² Craigavon and Banbridge Community Health and Social Services Trust

³ Marino Therapy Centre, 22 Marino Mart, Fairview, Dublin 3. Tel (01) 8333 126

etc. as well as the more obvious criteria such as maintaining a stable weight. The views of patients of patients are also an important outcome to take into account.

The models highlighted in the consultation document refer to the delivery of specialist services at Tier 3 however there is also a need to look at models of good practice for the delivery of services at Tiers 1 and 2.

5. CURRENT LOCAL SPECIALIST SERVICE PROVISION

The Councils agree that the consultation document contains an accurate picture of local specialist services. Within the greater Belfast area there is some degree of access to specialist services but there are long waiting lists and no access to an emergency assessment service. Within the rest of Northern Ireland people with eating disorders have no access to specialist services. The Councils agree with the Royal College of Psychiatrists description of services in Northern Ireland as 'woefully inadequate'.

6. GENERAL PRINCIPLES FOR SERVICE PROVISION IN NORTHERN IRELAND

The Councils welcome the principles set out in paragraph 6.1 that a model service should include: -

- a) Capacity to recognise eating disorders early in disease cycle
- b) Provision of training and guidance for primary care team
- c) Provision of training for local mental health services
- d) Individual agreed and regularly reviewed care plans

- e) Provision of specialist services
- f) Services specifically for children and adolescents
- g) Funding for self help groups
- h) Systems to monitor the quality of services provided

In our view it is important that all of the above principles are addressed in the development of services in Northern Ireland. We also believe that it is crucial that timely access to these services is ensured.

In addition, the Councils question whether a model service should provide for gender specific elements in that while most people affected by eating disorders are women, some are men. This issue should be considered when services are being developed in Northern Ireland.

- **Prevention**

The Councils welcome the principle of prevention and early detection as set out in paragraph 6.3. The public health strategy *Investing for Health* seeks to shift the emphasis from concentrating on the treatment of ill health to prevention by addressing the wider determinations of ill health.

The Council agrees that as most eating disorders start at school, teachers and health care workers should be provided with information on eating disorders and related issues. However the consultation document does not make any reference to the provision of information and work with young people as part of the prevention and early detection strategy. The Investing for Health strategy outlines that as part of a review of the education curriculum mental health awareness is included in the proposals for a specific programme for Personal Development. The objectives of this programme include personal understanding and

personal health. This type of programme may be one way in which awareness about eating disorders and also the building of the factors which may protect against developing an eating disorder (self-esteem etc...) could be addressed.

Information for young people on eating disorders could be produced in imaginative formats which would gain young peoples attention. A good example of this is the Health Promotion Agency's work on sexually transmitted diseases.

While it is outside the scope of this report many believe that discouraging the use of underweight role models in the fashion industry and the media should play a part in any strategy to prevent eating disorders.

- **Self-help/primary care services**

Self-help support groups such as those run by ADAPT, Derry Well Women and the Eating Disorders Association have provided an invaluable source of advice, support and information for patients, relatives and health and social services professionals over the years. It is important that the work of these groups is recognised and incorporated into the overall strategy for service provision for eating disorders. Adequate funding must be provided to enable these groups to meet the demand for their services, and in line with the DHSSPS Community Development Strategy, support should be provided for the development of support groups in areas where the potential for such groups exists.

Appropriate help at the first point of contact is vital. Paragraph 6.5 of the consultation document states that self help and support groups should

be publicised in GP practices. While the Councils support this measure, there is a greater need to publicise such groups more widely, particularly in schools, colleges, universities, community centres, pubs, clubs, etc as well as promoting them through the media.

- **Staff Training**

The Councils agree that a significant barrier to developing services is the lack of appropriately trained staff. Training at a number of different levels is required for the development of effective eating disorder services.

1. Awareness raising and training for primary care professionals is particularly important as the GP is very often the first point of contact with health and social services. GPs' awareness of eating disorders, their ability to recognise the symptoms, make the correct diagnosis and provide appropriate first line treatment must be improved. Special training for GPs (who may have received minimal teaching on the subject during their medical training) has been shown to improve the diagnosis of eating disorders⁴. In addition to training useful resources already exist. The Eating Disorders Association have produced a manual for use in primary care which highlights the signs and symptoms of eating disorders and provides information on how to help.

⁴ Hoek et al, (1995) cited in Noordenbos, G (1998). Eating Disorders in primary Care: early detection and intervention by general practitioners. In: W Vandereyken and G Noordenbos (Eds) The Prevention of Eating Disorders. Bath; Athlone Press.

2. Training for local mental health professionals is very important. If these services are to provide treatment for the majority of eating disorder patients within the locality and provide support to the primary care services, then in-depth training must be provided.
3. In order to support the above health professionals, specialist practitioners posts to work exclusively with people with eating disorders must be developed.

As well as providing training for health and social services professionals currently engaged in service delivery, it is essential that pre-registration training for future health and social services professionals including GPs, nurses, psychiatrists, psychologists dieticians, occupational therapists etc include eating disorders as a core element.

PROPOSED MODEL FOR SERVICE PROVISION IN NORTHERN IRELAND

The Councils support the four-tier model proposed. However the model proposed does not make any reference to the development of services specifically for children and adolescents. This is included in point (f) of the Eating Disorders Association's recommendations for a model service. If the services are to focus on prevention and early detection and intervention then this needs to be addressed as an increasing number of cases are being reported among those aged less than 10 years.

- **Tiers 1 and 2**

The main focus of the consultation document is Tier 3 – the specialist community team/outpatient/day hospital provision and Tiers 1 and 2 are

only briefly mentioned. There is no doubt that Tier 3 is very important but it is only one aspect of the proposed model and as such the Councils' view is that Tiers 1 and 2 need to be developed in tandem with Tier 3. This is essential if Tier 3 is to function in the manner proposed – specialist treatment for patients with severe disorders meanwhile Tiers 1 and 2 would provide treatment for the majority of eating disorder patients. Without the development of Tiers 1 and 2 in tandem Tier 3 would become overburdened and unable to function as envisaged.

Models of good practice for the delivery of services at Tiers 1 and 2 should be explored.

- **Tier 3**

In considering the options for Tier 3 it is not appropriate to maintain existing services. As described by the Royal College of Psychiatrists, current provision is “*woefully inadequate*”. Specialist services are only available in the Belfast area and even at that, cannot meet demand. There are long waiting lists and there is no scope to respond to requests for emergency assessments. There is inequity in that these limited services are not accessible in other parts of Northern Ireland – thus creating a postcode lottery.

The development of specialist expertise at Tier 3 is crucial to the provision of effective eating disorder services for Northern Ireland. In considering how this should be provided the preferred option of the Councils is for a regional centre with 2 outpost facilities. The benefits of this option are that: -

- It provides greater accessibility than a regional centre with one outpost facility.

- It is better able to provide a greater range of therapeutic interventions.

It is the types of treatments which will be available which is most important in terms of planning for effective eating disorder services. In which the Councils consider that it would have been useful to include this type of information in the consultation document. A wide range of treatments and therapeutic interventions such as those provided by the Royal Free Hospital eating Disorder Service should be included.

The limits of the model of one regional centre and two outposts is in terms of service accessibility. While certainly it is acknowledged that this model is considerably better than having a single regional centre, it is unlikely that this will overcome all problems with accessibility. In considering the possible locations of both the outposts and the regional centre, priority must be given to maximising accessibility.

It is not clear from the consultation document whether day patient services would be provided from the regional centre alone or also from the outpost facilities. If from the regional centre only, then consideration should be given to providing/facilitating hostel type accommodation for those living further away - similar to that provided by the St George's Hospital model.

The Councils agree that at least 2 outposts are required but it is recognised that because of the lack of specialist expertise at the minute within Northern Ireland, this may need to be provided on an incremental basis.

- **Tier 4 – Specialist in-patient services**

The Councils acknowledge that the experienced professionals required to staff an in-patient unit are not currently available in Northern Ireland in sufficient numbers for a sustainable service. However if specialist services can be developed and disorders diagnosed and treated at an earlier stage then hopefully the numbers requiring inpatient treatment can be reduced. However even with the development of Tiers 1- 3, it is probable that some individuals will still need to be admitted as an inpatient. The dilemma is where should they be admitted? Currently some patients are sent outside of Northern Ireland for specialist inpatient treatment but some are admitted to either a medical or general psychiatric ward at home. What will happen in the future? The document does not state whether *all* patients requiring admission will be offered specialist services in England or will some still receive inpatient treatment on at home? If the latter is likely to be the case what will be the basis of distinguishing which is most appropriate?

While the Councils appreciate that services must be cost-effective, it must be recognised that having to be admitted as an inpatient is a very stressful and traumatic time for both the individual concerned and their families. It can be important for many individuals to be close to their families and having to receive treatment outside of Northern Ireland is likely to increase further levels of distress to both the individual and their family however treatment within a general psychiatric or medical ward is not appropriate. Therefore the need for an inpatient unit in Northern Ireland should be kept under review as specialised services are developed.

CONCLUSION

In conclusion the four health and Social Services Councils welcome the proposal to develop eating disorder services in Northern Ireland. We support the 4-tiered model but consider that Tier 3 needs to be implemented in tandem with Tiers 1 and 2. We agree that inpatient facilities should be purchased from specialist facilities outside Northern Ireland for the present time but this situation should be reviewed once Tiers 1-3 have been established.