

A response to

'Because mental health matters

A new focus for mental health and wellbeing in Victoria

Consultation paper, May 2008'

Prepared by the

EATING DISORDERS FOUNDATION OF VICTORIA

(Eating Disorders Victoria)

31st July, 2008



Introduction

The Eating Foundation of Victoria (Eating Disorders Victoria) welcomes the Victorian Government's consultation paper "*Because mental health matters*" and applauds the initiative behind this paper. Eating Disorders Victoria has sent participants to stakeholder forums, a carers' forum and roundtable discussions that have been organised by the Department of Human Services. Eating Disorders Victoria has also been a keen participant in the Ministerial Advisory Committee on Mental Health (MAC) Eating Disorders Subcommittee, established from November 2007 to July 2008, to deliberate and provide advice to the MAC on eating disorder service issues, and in the Victorian Government's ongoing Community Advisory Committee on Positive Body Image.

Eating Disorders Victoria is a non-government organisation and DHS funded agency, and represents the voices of carers and consumers with eating disorders throughout Victoria. Eating Disorders Victoria is the Victorian's government's prime communicator with the eating disorder consumer and carer, and has a history of advocating strongly on their behalf for the evaluation, recognition of and improvement to consumer and carer experiences. Eating Disorders Victoria supports and promotes consumers' active involvement in their own treatment and recovery. We believe that this submission reflects the views of consumers and carers who have lived through, or are still living with, the experience of coping with an eating disorder in Victoria.

Eating Disorders Victoria is aware of and has provided input into separate submissions that have been prepared in response to this paper by the Mutual Support and Self Help Network of the PDRS sector, and by the Victorian Mental Health Carers Network, and for this reason has chosen to limit its comments in this submission to those areas of the paper which relate most directly to consumers and carers affected by eating disorders, and to concentrate on Focus Areas 1 to 4.

We trust that the Victorian Government will find value in the points made and the issues raised.

Background Information about the Eating Disorders Foundation of Victoria

Eating Disorders Victoria is the primary source of support, information, community education and advocacy for people with eating disorders, and their families, in Victoria. Our vision is to connect all Victorians whose lives are affected by eating disorders with the people, services and hope they need for recovery.

We are unique in Victoria in providing a comprehensive support and information service on all aspects of eating disorders. We are also unique in our provision of non-clinical help through a blend of qualified professionals and lived experience. Through our helplines, website, support groups, schools program and community education we have a direct impact on the mental health and wellbeing of thousands of Victorians every year.

Our core services and activities include:

- Telephone and email helplines, 9-5, five days per week – we provide the only specialised eating disorders helpline for consumers and carers in Victoria.
- Facilitated support groups – metropolitan and regional – providing a confidential and safe environment for recovery and learning through shared experience.
- Internet ChatRoom and MessageBoards - fully moderated for safety – reaching out to those who are isolated, or who require full anonymity.

- Specialist staff providing training and outreach to schools, fitness professionals, welfare workers, community workers.
- Specialist lending library of books and DVDs on eating disorders, self-esteem, self-help and related areas.
- Helpfinder database of health professionals and treatment facilities.
- Information service – free leaflets, booklets, highly rated website.
- Community education program - creating awareness in the community.

Some key statistics for Eating Disorders Victoria for the 12 months ending Jun 2008:
Total number of face-to-face support contacts: 227
Total number of telephone contacts: 2763
Total number of email contacts: 469
Total number of support group meetings run (metro/rural): 151
Total number of moderated Internet chat groups hosted: 118
Total number of professional development/community education activities carried out: 72
Total number of professional development / community education attendees: 2244
Total number of website hits: 1.1 million

General comments on this consultation paper

Eating Disorders Victoria welcomes the honesty and openness in this paper about many of the issues and gaps within the current system. The following are just a few of the points that particularly resonated with the experiences of our service users;

- “Many people are missing out on treatment. Many Victorians don’t see the warning signs, don’t seek help, or don’t know where to turn” (Minister’s message);
- “Victorians generally see the public specialist mental health system as a confusing maze, are unsure how to gain entry and even more unsure how to navigate once inside” (p19);
- “Services ... give inadequate attention to children and young people” (p13);
- “Our response lacks a strong prevention and early intervention capacity” (p13);
- “There is insufficient emphasis on making recovery, and the ability of people with a mental health problem to actively participate in our community, our main goal” (p13);
- “...individuals with mental health problems receive inadequate services compared to those with physical health conditions. For people with complex combinations of physical and mental health problems, the situation can be particularly unsatisfactory” (p13).

Eating Disorders Victoria commends the Victorian government on its “overarching vision” described on page 22 for mental health services in Victoria, which is in line with Eating Disorder Victoria’s vision (attached to this submission as Appendix 1).

Eating Disorders Victoria is strongly supportive of many of the key components of the planned new approach to mental health, particularly its emphasis on prevention, early intervention, recovery, and a properly integrated service response. All these are vital elements if the overarching vision is to be achieved.

Eating Disorders Victoria highly commends the Victorian government for including in its vision that mental health services should “meet contemporary community, consumer and carer expectations in respect to access, rights, equity and respect” (p22). This recognition of consumers and carers in the vision is long overdue.

Eating Disorders Victoria is disappointed to see that the Mutual Support and Self Help sector (MS/SH) is overlooked in this consultation paper. Eating Disorders Victoria contends that the services provided by MS/SH organisations are a vital and cost-effective component of the response to mental health needs in Victoria, and that this should be explicitly acknowledged in the Mental Health Reform Strategy.

Eating Disorders Victoria welcomes the recognition within this paper of the issue of key service gaps in eating disorders (p79-80). Eating Disorders Victoria is supportive and welcoming of the promised input of funding to boost current paediatric eating disorders services at The Royal Children’s Hospital, Southern Health and Austin Health (p80). However, we view this as a short-term band-aid approach which will not solve the major issues within the service system.

We would like to see much greater emphasis placed on the point that more comprehensive planning for service development is required to determine the future strategy for eating disorders services in Victoria. We urge that funding be allocated for the urgent development and implementation of such a strategy, building on the work of the MAC Eating Disorders subcommittee.

Eating Disorders Victoria views the announcement of a new 24/7 mental health information, advice and referrals helpline (p70) with considerable interest. We would welcome more information, consultation and involvement in the development of the new helpline service.

Eating Disorders Victoria is concerned with regard to the omission from this paper of any reference to the work it carries out, particularly when discussing how to improve the outcomes for children, young people and adults with an eating disorder (p80).

The work of Eating Disorders Victoria as a statewide specialist organisation within the community, in promoting eating disorder prevention, identification/early intervention and recovery from eating disorders, is as important to the achievement of the vision outlined within this paper as the work of the Centre for Excellence in Eating Disorders (CEED). This should be made clear in the paper and supported in the Mental Health Reform Strategy.

Detailed Comments – Part A

Vision

The “overarching vision” and its descriptive points (p22) have some excellent components which are in line with Eating Disorder Victoria’s vision (Appendix 1).

We suggest that the third component of the vision should be expanded to read:

- “People with severe mental health problems have access to a range of fully integrated, age-appropriate stepped care options, including in-patient (bed-based), day-patient and out-patient services, that enable them to receive the least intrusive care appropriate to their condition, including urgent and acute medical care when required.

We further suggest that the final point of the vision be expanded to put further emphasis on recovery and to recognise that support is required for the chronic impacts of mental illness after clinical treatment has ended:

- People recovering from or living with a mental health problem are supported to participate fully in society and the workforce without stigma or discrimination; support does not cease when clinical treatment is ended but carries on throughout the recovery journey.

Principles

The “overarching principles” that follow the vision are also commended.

Again we suggest some changes and expansion of one principle:

Principle 4 – Recovery orientation. This principle tries to address treatment options and support for recovery as one issue, when really these are two areas. It fails to recognise the chronic aspect of many mental illnesses, and that support for recovery needs to extend for a long period (in many cases, years) beyond the conclusion of clinical treatment. It also fails to explain the rationale behind the need for options in treatment.

We suggest that the principle be expanded and divided to read:

Principle - Treatment options

- Recognising that there is no ‘one size fits all’ approach to complex mental health issues; and offering clients, carers and clinicians flexibility to choose the best approach in each situation by promoting access to a range of responsive, client-centred, evidence-based effective treatment options.

Principle – Recovery orientation

- Recognising that the process of recovery is not linear and that full recovery can take months or even years; ensuring the optimal environment for recovery by the provision of effective, coordinated support for consumers and carers alike, both during clinical treatment and after treatment has concluded for as long as it is required.

Detailed Comments – Part B

Focus Area 1: Prevention

Eating Disorders Victoria applauds efforts to make prevention and promotion a more fundamental part of the State's approach to mental health.

Questions from the paper:

What are the most promising avenues for further work across families, schools, early childhood settings and workplaces?

Are there other settings that should be considered?

What partnerships should be developed to support a coordinated approach to progress in the above settings?

In our experience, supported by research, Eating Disorders Victoria has found that the most effective approach to health promotion and disease prevention within schools is to work directly with the schools professionals – teachers, school counsellors, health and welfare workers – in an interactive workshop format, to help them to appreciate the risk factors and protective factors associated with mental health problems generally and those particularly associated with eating disorders; to assist them in identifying warning signs and early intervention strategies; and to empower them with ideas and strategies for engendering a whole-of-school culture which includes positive role modelling, peer support and which enhances self-esteem, positive body image and other protective factors.

Another promising avenue is to work in a similar manner with fitness professionals and coaches within schools, gyms and fitness centres. Many of these professionals have close contact with children and young adults and, like teachers, are well placed to spot early warning signs of an eating disorder or exercise compulsion, to support positive body image and to educate their clients about appropriate levels of exercise and fitness.

Through its Deliver professional development programs targeting schools professionals, fitness professionals, coaches and welfare workers, and its Body Positive awareness initiatives aimed at workplaces and the general community, Eating Disorders Victoria has positioned itself as a key player in this area with a strong role in mental health promotion and eating disorders prevention through schools, gyms and fitness centres, workplaces and communities.

Within the marketplace there are many providers of programs targeting different aspects of mental health promotion, as well as physical health programs tackling healthy eating, healthy activities, obesity management etc, for students. There are rather fewer programs tackling the professional development rather than universal education for students, or providing ongoing support for cultural change. Eating Disorders Victoria envisions the development of a multi-component 'mind and body friendly' program, whereby key mental and physical health areas could be identified, and providers' programs grouped together into each category. Schools could be encouraged to complete staff and/or pupil education in all components and to apply for 'mind and body friendly' accreditation. Such a program would require the partnership of participating organisations and would need to be backed by multi-departmental Government support. Participating organisations could include existing providers of physical and mental health education programs such as Eating Disorders Victoria, Go For Your Life, YMCA, YWCA and many others.

Question from the paper:

What aspects of the current approach to suicide prevention need further improvement?

Research has shown that eating disorders have the highest mortality rate of any psychiatric illness, and that there is a high rate of intentional suicide associated with eating disorders. Suicide prevention and intervention skills are covered within Eating Disorders Victoria's in-house training for volunteers and staff, and we are currently applying for philanthropic funding to assist us to run more comprehensive suicide prevention and intervention training to up-skill volunteers and staff in this area.

As part of improving the approach to suicide prevention, The Mental Health Reform Strategy should include fully funded suicide prevention and intervention training for all mental health staff and volunteers working with groups identified as having a heightened risk of suicide.

Focus Area 2: Early Intervention

Eating Disorders Victoria welcomes the focus on improving identification and earlier intervention in order to achieve better outcomes for children, young people and families. We agree that this is a key area in which there is much improvement needed.

Questions from the paper:

Should a stronger problem identification capacity be developed? If so, what should be its key features?

This paper states:

- “Schools are in a unique position to identify and respond to children and young people with problems in social and emotional development or emerging mental health issues”; (p58) and
- “A comprehensive professional development program, involving specialist mental health and early childhood services/schools support staff, could promote skill development and collaborative practice” (p59).

Eating Disorders Victoria agrees strongly with these statements; but we suggest that a professional development program for early identification needs a wider audience than the statement implies. Professional development for all school staff (not just support staff) can greatly increase their understanding of the onset points, potential triggers and warning signs for emerging mental health problems such as eating disorders, and would assist in early identification of children and young people at risk and in need of referral.

Through the schools professional development workshops already referred to, along with the Secondary Schools Resource Manual, Eating Disorders Victoria aims to improve the level of understanding within schools professionals – teachers, counsellors, health and welfare staff - of the early warning signs shown by children who may be developing disordered eating and/or other mental health problems; and to highlight the avenues open to them for obtaining referrals advice. Further support within the Mental Health Reform Strategy for programs of this nature would be very beneficial.

Parents, too, often have no idea where they can go to receive support and advice. Early intervention could be greatly improved if parents were better informed and had a better understanding of where to go for help. Like a number of MS/SH organisations Eating Disorders Victoria runs a telephone information, advice and referral service to assist in this process; but we require a greater public awareness that this service exists. Potentially this

could be achieved by stronger interfaces with the planned new mental health information, advice and referral helpline - this will be referred to later in our submission in Focus Area 3.

The first stage in the referral process for families of the majority of children with eating disorders is the local GP; yet Eating Disorders Victoria continues to receive calls from distressed parents and carers who have encountered a significant lack of knowledge and understanding about eating disorder signs and symptoms in their local GP. Misconceptions still abound - parents have been told their child cannot have an eating disorder because they are too young; are normal weight for their age; or are male, for example. This lack of knowledge causes major difficulties with regard to early intervention occurring. Better access to quality education in eating disorders for practising GPs and medical students is urgently required. Prior to its reorganisation in 2007 the Centre for Excellence in Eating Disorders (CEED) did some excellent work in this area. With the new narrowed focus of CEED's operation, training for GPs has been significantly cut back. CEED needs to be strengthened and adequately resourced to resume and increase its work in this area.

Questions from this paper:

What are the appropriate and viable options for structuring services for adolescents and young adults? Are there distinct groups, defined by age or type of mental health problem that need different interventions? What services should deliver these interventions?

Children and young people displaying risk factors such as difficulties around eating, struggling with self-esteem and body image issues, engaging in weight-loss dieting, are at-risk populations for developing eating disorders. Eating disorders in children can have devastating acute and long-term physical, psychological and social impacts. There is international agreement that, due to the complex combination of physical and mental health problems to be managed in the treatment of eating disorders, services need to be delivered by multidisciplinary teams.

Specialist eating disorder services should be developed for children and adolescents with eating disorders, that are age-appropriate (severe eating disorders are occurring as young as 8) and allow for staged transition to adult services.

Eating Disorders Victoria is heartened to see that "services will place stronger emphasis on engaging and supporting families through providing early education about problems and involving them in treatment and recovery planning so that they know how to seek assistance if problems worsen or recur" (p64). Powerful evidence (from over 40 randomised controlled trials carried out over 30 years) supports the inclusion of family and other carers in the treatment and care of their unwell relative. Eating Disorders Victoria has long understood the need for support and information for families of people with eating disorders. In response to this need Eating Disorders Victoria has developed and runs a 4-part psycho-educative program for families and carers of people with eating disorders, which seeks to provide them with comprehensive information about the ways the sufferer may be affected by the illness, an understanding of their own response, coping skills, practical strategies such as meals support and recovery planning skills. We suggest that Eating Disorders Victoria is well placed to assist with the development of this emphasis on family support for people with eating disorders.

Focus Area 3: Access

Eating Disorders Victoria agrees that access to 'right time, right place' mental health information and services is an important focus.

Eating Disorders Victoria views the announcement of a new 24/7 telephone mental health information, advice and referrals helpline (p70) with considerable interest. Many MS/SH services already operate specialised telephone information, support and referral services in their areas of speciality, often with a minimal budget, utilising trained volunteers with life and/or professional experience in the specialist area to provide the service. Some also provide limited supportive counselling. The establishment of this new helpline raises a number of questions. How will the new helpline interface with existing specialised helplines? Will the operators be fully trained to provide detailed formal and informal advice on all aspects of the wide range of mental health issues, or will this role remain with the MS/SH services? If the new mental health helpline exists primarily to provide linkage through to appropriate services, how will the different roles of the helplines be promoted and explained to the community without causing further confusion? Since the Victorian government has recognised the value of helplines and is prepared to invest considerable capital in this new service, will there be complementary additional funding and service promotion provided to existing helplines, which currently provide service to thousands of consumers and carers each year typically on shoestring budgets?

We would welcome more information, consultation and involvement in the development of the new helpline service.

Focus Area 4: Specialist Care

Eating Disorders Victoria welcomes the focus and goals of Focus Area 4, to meet the needs of people with severe mental health problems – building responsive specialist public mental health services.

The area of primary concern to Eating Disorders Victoria within this Focus Area is the issue of key service gaps in eating disorders (p79-80). A mental health focus that aims to address this particular need is long overdue and greatly welcomed.

Questions in this paper:

What reforms are required to improve the early identification and treatment and continuity of care of all people with eating disorders?

How should we consider the respective roles of local, regional and statewide services in this area?

It is stated within this paper that “the Eating Disorder Service Mapping Project (2006) found that care for people with eating disorders was far from optimal, with growing demand and increasingly younger clients requiring specialist treatment and care” (p79). This statement, while strong, requires some reinforcement. The Eating Disorder Service Mapping Project, while highlighting some of the deficiencies in services, did not go nearly far enough in defining the gaps in the provision and the continuum of eating disorder treatment services in Victoria in 2006. In particular it failed to highlight the fact that Victoria has no dedicated specialist inpatient unit for children and adolescents with eating disorders. With numbers of young children with severe eating disorders increasing in recent years, the need for a specialised unit has also increased.

Eating Disorders Victoria is supportive and welcoming of the input of funding to boost current paediatric eating disorders services at The Royal Children’s Hospital, Southern Health and

Austin Health (p80). However, the provision of additional funding for current treatment services, while welcome, is a short-term band-aid approach which will not solve the major issues within the service system.

We would like to see much greater emphasis placed on the point that more comprehensive planning for service development is required to determine the future strategy for eating disorders services in Victoria. This strategy is urgently required. We suggest that funding be set aside for the development and implementation of such a strategy, building on the work of the MAC Eating Disorders subcommittee (see below).

The Ministerial Advisory Committee on Mental Health (MAC) established a subcommittee in November 2007 to deliberate on eating disorder service issues. This subcommittee identified a wide range of issues in the service system relating to

- Gaps in the continuum of care
- Lack of families support
- Lack of leadership and research
- Workforce issues
- Equality of access to specialist services and beds
- Varying quality and effectiveness of service

The MAC Eating Disorders Subcommittee has produced a report with initial recommendations which will go to the Minister for Mental Health in August 2008 – Linking together: Treatment of Eating Disorders in Victoria. The recommendations of this report should be incorporated into the Mental Health Reform Strategy.

Eating Disorders Victoria is concerned with regard to the omission from this consultation paper of any reference to the work it carries out, particularly in the discussion on how to improve the outcomes for children, young people and adults with an eating disorder (p80).

The work of Eating Disorders Victoria as a statewide specialist organisation within the community, in promoting eating disorder prevention, identification/early intervention and recovery from eating disorders, is as important to the achievement of the vision outlined within this paper as the work of the Centre for Excellence in Eating Disorders (CEED).

We suggest that an additional dot point be inserted at the end of this section (p80), as follows:

- Providing additional resources to the Eating Disorders Foundation of Victoria to expand its schools and community education programs, web-based and telephone information and referral services, and to further develop consumer and carer support group structures including new support groups in partnership with clinical mental health services.

Eating Disorders Victoria welcomes the goal to build a more proactive system of specialist community-based mental health care that is geared to early intervention, relapse prevention and recovery. We are encouraged to see that there is a move towards an integrated response between clinical, rehabilitation and primary care services covering the individual's treatment, psychosocial rehabilitation and recovery needs (p77).

Within this integrated approach, there remains a great need for strengthening of the work of the PDRSS, and the MS/SH sector in particular. An area of concern to us is that the value and input of MS/SH organisations as a key part in the effective support of psychosocial rehabilitation, recovery and relapse prevention is not covered in this paper. This omission,

together with the lack of recognition of the work of Eating Disorders Victoria within the eating disorders service system, implies that MS/SH agencies are not considered to be active and key participants within the specialist public mental health system.

Eating Disorders Victoria contends that the services provided by these organisations are a vital and cost-effective component of the response to mental health needs in Victoria, and that this should be explicitly acknowledged in the paper. They harness and combine the goodwill and expertise of hundreds of trained volunteers, the lived experiences of consumers and carers, and specialist staff knowledge to provide community outreach and prevention initiatives, individual and group psychosocial support, enhancement of coping skills, recovery promotion and relapse prevention.

The services provided by MS/SH agencies should be included in the Mental Health Reform Strategy as a core component of the specialist mental health system.

Questions in this paper:

What key policy directions should be considered over the next 5-10 years to achieve improved consumer empowerment and self-determination?

What strategies/mechanisms are required to better support the active involvement of consumers in their treatment and care?

What are the best models for supporting a carer sensitive approach in the mental health system?

Eating Disorders Victoria is greatly heartened to see a goal within this Focus Area which focuses on improving consumer and carer experiences, strengthening their participation in service development, supporting consumers' active involvement in their treatment and care and addressing the diverse needs of carers.

Eating Disorders Victoria is the Victorian's government's prime communicator with the eating disorder consumer and carer, and has a history of advocating strongly on their behalf for the evaluation, recognition of and improvement to consumer and carer experiences. We keep a database of consumers and carers who have volunteered to speak at public and private forums about their experiences, some of whom have also participated on government advisory bodies as consumer/carer representatives. Eating Disorders Victoria has long supported and promoted consumers' active involvement in their own treatment and recovery.

One obvious area for policy direction in order to achieve this goal would be to strengthen and enhance the role of consumer and carer based agencies such as Eating Disorders Victoria and other MS/SH agencies. Many MS/SH agencies are consumer based with consumers (primarily recovered) and carers voluntarily involved in many aspects including governance, provision of support services and community education.

Consumer-based MS/SH agencies and carers networks are ideally placed to assist in the development of many parts of the Mental Health Reform Strategy, particularly with respect to prevention and health promotion, identification/ early intervention and recovery support. We reiterate our call to ensure that MS/SH agencies are given due attention within the Mental Health Reform Strategy.

Appendix 1

Eating Disorders Foundation of Victoria – Mission, Values and Vision

Mission

Eating Disorders Victoria is the primary source of support, information, community education and advocacy for people with eating disorders and their families in Victoria.

We connect those whose lives are affected by eating disorders with the people, services and hope they need for recovery.

Values Statement

Eating Disorders Victoria has adopted the following values in all its relationships:

- Respect
- Acceptance
- Understanding
- Empathy, and
- Hope

Our Vision

We envisage a future where the incidence, duration and impact of all eating disorders is reduced and ultimately eradicated.

This is a future where:-

- Our culture supports and promotes people engaging in healthy lifestyles without dieting;
- Diversity of size, shape and body image is celebrated among men and women;
- People live in a society which values, protects and enhances their self-esteem at all ages;
- The causes, prevention and treatment of eating disorders are well researched, better understood, and the resulting knowledge is available;
- Eating disorders are recognised in all levels of the community as serious illnesses which require professional treatment and early intervention;
- GPs, community health workers, fitness professionals and school staff are able to recognise the early warning signs of an eating disorder and are equipped to intervene or refer as appropriate;
- People with eating disorders can access age-appropriate, publicly funded, evidence-based treatment at the earliest possible time;
- There is consistent clinical service provision across Victoria, with equitable access throughout metropolitan and rural areas;
- Non-clinical support is available for all people with eating disorders and their carers, for as long as and wherever they need it; and
- People experiencing eating disorders and their carers are treated with respect, acceptance, understanding, empathy and hope throughout treatment and recovery.