Eating Disorders
Legislative Report

Submitted by the Department of Health and Human Services

November 2, 2005

Executive Summary

Legislation

In the recent session of the Legislature, LD 239 was enacted. The Department of Health and Human Services was directed to convene an eating disorders workgroup to build partnerships as well as to develop a report on inpatient and outpatient resources for preventing, identifying and treating eating disorders and to submit this report to the Health and Human Services Committee by November 2, 2005. (See Appendix A)

Eating Disorders Described

Eating disorder diagnoses include a variety of illnesses such as anorexia nervosa, bulimia nervosa, binge-eating and unspecified eating disorders. These illnesses affect all ages, but are more common in adolescents, young adults and females. They are serious mental and physical health problems that can have life-threatening consequences. Coordination between different disciplines is recognized as critical to effective prevention and treatment for eating disorders.

Assessing Available Resources

The Eating Disorder Workgroup assessed inpatient and outpatient services for those affected by eating disorders as directed in the resolve. Through research and surveying, the workgroup identified barriers to accessing appropriate treatment services for patients, families and mental health and medical professionals.

These include:

- Location and geographical maldistribution of services
- Limited availability of services and professionals for persons of all ages
- Lack of professional development and training for providers
- Inconsistent quality of services including utilization of evidence-based practices
- Lack of a system which provides for coordination of care that supports a strong referral mechanism between community providers and in-patient programs
- Lack of understanding of insurance coverage and reimbursement procedures

Recommendations

Based on the recent and historical findings through research, statistical information and personal accounts, the Eating Disorders Workgroup recommends the following:

- Increase awareness of the problem of eating disorders at the state and local levels,
- Develop and implement a comprehensive system of services and resources, and
- Continue to assess outcomes and effectiveness of these efforts in terms of reducing the prevalence of eating disorders, reducing the long-term emotional and medical consequences and increasing the cost effectiveness of appropriate treatment on individuals, families and governments.

Introduction

Disordered eating involves a constellation of symptoms and behaviors not limited to self starvation, self induced vomiting, abuse of diuretics and laxatives, compulsive gorging and insatiable cravings, and distorted self perceptions of body images. Eating disorders are characterized by the presence of extreme emotions, attitudes and behaviors towards weight and food. Often a level of severity is required for a medical diagnosis. *Anorexia nervosa* is characterized by a perception of being fat with extreme dieting and/or exercise when in fact the patient is underweight. *Bulimia nervosa* is commonly characterized by binge-eating followed by self-induced vomiting, with the perception of being fat and a fear of the inability to stop eating voluntarily. *Eating disorders unspecified* is a diagnosis used when a person does not meet all of the clinical symptoms related to anorexia or bulimia or has other symptoms that show unhealthy behaviors related to weight and eating[1]. However, those with sub-clinical disordered eating do experience similar symptomology, exhibit these behaviors and suffer the related consequences of a diagnosed eating disorder. The identification, prevention and treatment, are further complicated by commonly co-occurring behavioral and physical health problems.

The complexity of these disorders cross over multiple fields of care requiring comprehensive treatment services involving coordination across disciplines. Inpatient and outpatient programs serve to identify, prevent, and treat eating disorders. In addition they provide information, education, and support to all persons impacted by eating disorders in order to reduce its prevalence and decrease the medical complications and emotional harm associated with the disorders. Reports on recovery rates indicate that up to 20% of people with serious eating disorders die without treatment. With treatment this number decreases to 2-3%[2]. Evidence suggests that family, friends and those working with individuals with an eating disorder are significantly affected by these disorders, and also benefit from services to increase their capacity to assist in the recovery process.

Statistical Information

Determining accurate statistics about eating disorders is difficult, in part because physicians are not required to report these illnesses. Diagnostic information can be skewed as symptoms and behaviors of an eating disorder are often co-occurring with the primary diagnoses of other psychiatric or medical conditions and consequently may be underreported. There is also a significant proportion of people who have sub-clinical or threshold eating disorders not captured in diagnostic data but who also suffer similar physical and mental consequences. The secretiveness associated with these disorders as well as other barriers to connecting with appropriate treatment services present additional challenges in assessing data on eating disorders.

Key data (United States and Maine):

- In the United States, as many as 10 million females and 1 million males have eating disorders[3].
- More than 90% of those with anorexia and bulimia are young women between the ages of 12 and 25. National studies suggest that 1% of young women between ten and twenty have

[1] Source: Anorexia Nervosa and Related Eating Disorders, Inc. website, downloaded 10/31/04
[2] Source: Anorexia Nervosa and Related Eating Disorders, Inc. website, downloaded 10/6/04
[3] Source: Anorexia Nervosa and Related Eating Disorders, Inc. website, downloaded 10/6/04

anorexia, 4% of young adult women have bulimia, and 1% of all women have a binge-eating disorder[4].

- Over 1,000 outpatient hospital visits with eating disorders as the primary diagnosis occurred in 2002 in Maine, resulting in charges exceeding $1,140,000[5].
- Ninety-five individuals in Maine were hospitalized in 2003 due to eating disorders, approximately 50% of whom had anorexia nervosa listed as the primary diagnosis[6].
- In 2003, 64% of high school girls reported they are currently trying to lose weight. The same data shows that, based on calculations using self reported height and weight measurements, 22% of these girls are overweight or at risk of being overweight. Of those trying to lose weight, 24% use fasting, 10% use pills or laxatives, 10% vomit for a total of 44%.[7].

Response in Maine

The Maine Legislature created a commission in 1998 to study eating disorders in response to the growing concern about the problem in Maine, the acknowledgement of limited funding and a reported lack of interventions to combat these disorders. The Commission included individuals affected by eating disorders, their families, public health and treatment experts and representatives from various State departments. Three crucial findings reported by the Commission were:

- The limited data available on the prevalence of eating disorders.
- Few existing programs for education or prevention.
- Too few treatment resources including inpatient/outpatient services, community support groups and independent treatment providers statewide.

Recommendations based on these findings were submitted to the Legislature. However, progress was limited as no resources were provided to fully implement the recommendations.

The Eating Disorders Workgroup's Current Activities

In 2004, the Eating Disorders Workgroup was re-convened as a public-private partnership. The workgroup is co-chaired by Public Health staff and Mainely Girls, a Maine-based non-profit organization. The workgroup includes representatives from hospital programs as listed in the resolve, the Department of Health and Human Services, the Department of Education and other community advocates, primary care and mental health providers.

The workgroup reviewed the 1999 Commission report and identified areas in which some progress has been made, specifically in the areas of prevention and comprehensive health education. Subsequently, short and long term priorities were developed with an emphasis on a one-year action plan integrating eating disorders prevention, identification and treatment into existing programs and initiatives. For example, partnering with existing obesity prevention and behavioral health initiatives, such as the Healthy Maine Partnerships and the Women's Health Initiative are strategies that were identified by the workgroup. The workgroup also agreed to move forward with initiatives on provider training and the development of a web-based referral system. The workgroup's efforts will include integration into the State Health Plan when it is

[4] Source: Source: Anorexia Nervosa and Related Eating Disorders, Inc. website, downloaded 10/6/04
[5] Source: Maine Health Information Center 2002
[6] Source: Maine Health Data Organization 2003
[7] Souce: Maine Youth Risk Behavior Survey 2003

released. The workgroup's activities will also focus on addressing the demand for quality, comprehensive treatment services with an emphasis on evidence-based practices which has been identified as a critical need throughout Maine.

Following the passage of LD 239, the workgroup expanded its membership. (See Appendix B for a list of active and invited members.) The workgroup then focused its efforts on assessing inpatient and outpatient resources for preventing, identifying and treating eating disorders in persons of all ages. To efficiently and effectively succeed in its charge, the Eating Disorder Workgroup divided its membership of varied stakeholders into two subcommittees: treatment and prevention. Each subcommittee further refined their priorities to meet the charge of LD 239. These subcommittees have met regularly since June 2005.

Prevention Subcommittee

Given limited resources for new initiatives, the prevention subcommittee sought to identify existing resources and avenues in which eating disorder prevention education could be incorporated. These included school health education curricula and community parenting programs. Primary audiences for prevention messages that have been identified include parents, school personnel, primary care and mental health providers and other youth-serving professionals, and youth. There is a need for both primary prevention messages that emphasize healthy eating, physical activity and positive body image, as well as messages that focus on warning signs, early identification, and obtaining help.

Anecdotal reports from various committee members indicate that educators are often uncertain as to how to address eating disorders in the classroom since they do not want to cause harm. They have received conflicting information on whether or not including Eating Disorder information in the curriculum may be more harmful than effective. Clear guidance on what to include and what not to include is needed. In addition, the group identified the need to teach about human growth and development and to develop positive body images and self-esteem and primary prevention messages for students.

Three existing resource centers have been identified that have eating disorder prevention materials: the Health Education Resource Center at University of Maine – Orono Campus, the Curriculum Resource Center of Maine (through the Department of Education), and the Information Resource Center at the Office of Substance Abuse. The subcommittee identified the Department of Education's "Key Concepts" process as a method to integrate school-based eating disorder prevention with the Maine Learning Results. Through this process, linkages between the Maine Learning Results for all levels (kindergarten through high school) will be identified by eating disorder experts and reviewed by the Department of Education. Other priorities identified by the subcommittee include identifying and linking to existing web-based resources and developing Maine-based fact sheets for the key audiences identified. The middle school population is an age group of special interest and first priority since the process of puberty and both physical and social developmental changes make middle school youth vulnerable to mass media messages that glamorize thinness.

Treatment Subcommittee

The Treatment subcommittee identified its main priority as developing strategies to assess the availability of existing statewide resources that provide services to address eating disorders. Collectively the members decided to use surveying as one approach. Survey methodology can be viewed in Appendix C. Limitations to this survey process and consequently the application of the data include the absence of resources for consultation on survey methodology, design and distribution, low response rate, and the lack of resources such as staff, time and funding. Other methods included researching information collected by insurers as well as collaborating with other stakeholders who had knowledge and familiarity of resources for eating disorders that are readily available to the public and to professionals actively seeking this information.

Survey Findings

A total of 572 surveys were received by October 5, 2005. The total number of respondents included 424 mental health providers, 133 medical practices/rural health centers and 15 hospitals. Survey responses indicated that barriers to patients accessing appropriate treatment for eating disorders include location of services, the availability of services to all ages, reimbursement procedures, and lack of opportunity for professional training and coordination. One respondent wrote,

> "There seems to be a paucity of adequate providers to treat those who are seeking treatment, combined with a high demand for services. I have not had good luck finding good nutritionists for these patients. When there is a need for more intensive service (partial hospital, inpatient), appropriate focused treatment for these patients is either unavailable or inaccessible, due to distance. I do not know of any psychotherapy groups (other than support groups) for eating disorder patients in the Bangor area. Lack of reimbursement by insurance has been a terrible problem for families devastated by this disorder."

Location of services:

- Only one hospital response indicated a designated bed/unit specific for treating patients with eating disorders. Survey results show outpatient programs exist in three out of fourteen hospitals.
- Of the surveys submitted by mental health and medical practice professionals, less than 50% reported providing treatment for persons with reported or suspected eating disorders. These respondents indicated that 12% of the services offered were specific to treating eating disorders. Services offered in mental health practices included individual, group and family counseling and referrals to medical providers.
- Over 90% of medical practices and rural health centers surveys reported providing general services that were appropriate services for treating eating disorders. These included treatment monitoring and referrals to mental health professionals and dietitians, but these services were not identified as specialized for eating disorders.

Accessibility for persons of all ages:

- Approximately 80% of treatment services are available to people aged 14 and older.
- Less than 45% of these services are available to younger populations (13 and younger), with almost half of these limited to Cumberland and Penobscot counties.

- Data grouped by age on primary diagnoses of anorexia nervosa, bulimia and eating disorder unspecified shows that the number of adolescents aged 0-13 more than doubled from 2000-2002.

Professional training and coordination:

- In addition to their own services, over 90% of survey respondents reported referrals to other professionals as an extension of treatment.
- Survey respondents most often selected mental health providers, dietitians and PCP/pediatricians for coordination and referrals.
- Less than 10% of respondents from medical practices and less than 20% from mental health providers reported that they refer to a hospital or emergency room.
- Over 27% of medical practices reported either limited knowledge or a lack of knowledge of resources and/or services in Maine that would be appropriate for treating an eating disorder.
- Approximately 37% of mental health providers reported clinical staff having completed an average of 1-10 hours of specialized training. Over 20% reported no training.

Resource List

108 respondents elected to include individual or organizational contact information in their survey response to be included in a state-wide resource list. Teen and Young Adult Health Program staff in the Maine Department of Health and Human Services are in the process of confirming providers' information on this resource list. When this is completed, it will be disseminated throughout the state via provider list serves and made available on the Internet, with periodic updates. Other referrals are available through the emerging statewide 211 system run by Ingraham. They have been contacted to determine whether these resource lists could be merged and the workgroup is awaiting their response.

The work group also identified lists of self-identified eating disorder specialists who are part of private insurance networks. This resource information is already available on the Internet via the insurers' websites. Some of these providers are also included on the newly developed resource list, but others are not since they did not respond to our survey.

Conclusion

The work conducted by the Eating Disorder Workgroup over the last six months has identified the existence of some resources. However, it also appears that there are significant gaps in services, especially for younger patients, as well as gaps in training, and prevention resources. The workgroup has agreed to continue to meet and move forward on several identified priorities that can be accomplished without additional human or financial resources.

Closing the larger gaps cannot be addressed without additional resources. The workgroup has sought national expert opinion on a comprehensive system to address the full spectrum of prevention and treatment of eating disorders that includes public awareness, evidence-based treatment options, trained regional teams and evaluation, appropriate for the level of need in Maine.

Detailed Recommendations:
The Eating Disorder Workgroup recommends the following Legislative actions:

- Resolution to recognize the National Eating Disorders Awareness Week in the last week of February, and to recognize the growing needs for the prevention, early identification and treatment of eating disorders, and to support the continuing work on outcomes-based solutions.
- Allocate $1 million to develop a System for Excellence, loosely based on New York's Comprehensive Care Centers system, and using a regional approach to establish resources in all parts of the state for male and female adults and children and youth of all ages.
    - Identify and disseminate prevention resources, raise public awareness, and provide training for parents, educators, dietitians, and dental care, primary care and mental health providers.
    - Research effective treatments and develop policies that include evidence-based practices for treatment systems, workforce development and reimbursement.
    - Develop community-level resources and support for health care generalists.
        - Consultation, including video conferencing, paid through public and private insurers.
        - Create teams in communities to provide support and improved treatment.
        - Develop community-campus partnerships.
        - Train primary care providers for better early identification.
    - Implement data collection, analysis and evaluation to track and improve these efforts.

Given limited available resources, the Department of Health and Human Services recommends continuing to integrate Eating Disorders into existing initiatives both public and private through the continuing commitment of the Eating Disorders Workgroup.

CHAPTER 33

H.P. 178 - L.D. 239

Resolve, To Develop a Partnership To Prevent, Identify and Treat Eating Disorders

Sec. 1. Eating disorders partnership. Resolved: That the Department of Health and Human Services shall convene an eating disorders work group to develop a partnership between the department and geographically representative hospitals throughout the State to prevent, identify and treat eating disorders, including leveraging current programs, initiatives and resources and disseminating information on eating disorders. The work group must include the Superintendent of Insurance or a designee of the superintendent and representatives of the department, the Maine Hospital Association, hospitals, medical centers and health care providers, consumers and their families and other interested parties; and be it further

Sec. 2. Report. Resolved: That the eating disorders work group shall report by November 2, 2005 to the Joint Standing Committee on Health and Human Services on inpatient and outpatient resources for preventing, identifying and treating eating disorders in persons of all ages.

Appendix B
Eating Disorder Workgroup Membership

The following people attended at least one meeting of the eating Disorders workgroup and/or assisted in the development of the Eating Disorder survey and/or report:

Bridget Bagley, Maine Dept. of Health and Human Services, Bureau of Health, Teen and Young Adult Health Program Manager
Nancy Birkhimer, MPH, Maine Dept. of Health and Human Services, Bureau of Health, Teen and Young Adult Health Program Manager (co-chair)
Andy Cook, MD, Maine Dept. of Health and Human Services, Children's Mental Health, Medical Director
Leanne Dodge, Maine Dept. of Health and Human Services, Office of Substance Abuse, Prevention Specialist
Liane Giambalvo, Diabetes, Endocrine and Nutrition Center, Eastern Maine Medical Center
Ellen Grunblatt, MD, University of Maine at Farmington
DeEtte Hall, RN, Maine Dept. of Education, School Nurse Consultant
Victoria Kuhn, Strategist, Anthem Blue Cross Blue Shield
Janet Leiter, Maine Dept. of Health and Human Services, Bureau of Health, Maternal and Child Health Nutrition
Mary Mayhew, Maine Hospital Association
Dan Meyer, PhD, Sociologist, Maine Dartmouth Family Practice Residency Program
Grace Morgan, Maine Dept. of Education, Health Education Consultant
Ida O'Donnell, LCSW, Private Therapist
Mary Orear, Mainely Girls, Executive Director (co-chair)
Joan Orr, CHES, Maine Center for Public Health, Project Director
Katherine Pelletreau, Maine Association of Health Plans, Executive Director
Paul Puchalski, Mercy Hospital, Eating Disorders Program
Lauralee Raymond, Maine Women's Lobby
Anita Reynolds, Maine Dept. of Health and Human Services, Office of Substance Abuse, Information and Referral Center
Representative John, Tuttle, Maine Representative
Ricki Waltz, Lincoln Academy School-based Health Center
Burma Wilkins, Mercy Hospital Board Member
Diane Williams, Nurse Consultant, Maine Department of Professional and Financial Regulation, Bureau of Insurance

The following individuals were invited to participate and had several opportunities to comment on the work group progress and the report, but did not attend any committee meetings or otherwise actively participate:

Martha Allen, Family Crisis Center, executive assistant
Wendelanne Augunas, Penobscot Bay Medical Center, Family Coordinator
Terri Bly, University of Maine at Orono, Health Center
April Boulier, Health Center, University of Maine at Orono
Representative Richard, Burns, Maine Representative
Kristen Carr, former patient
Anne Connors, Project Specialist, University of Southern Maine, Muskie School of Public Service
Norma Dreyfus, MD, local physician, adolescent health specialist
Senator Beth Edmonds, Maine Senator
Jaki Ellis, CHES, Maine Dept. of Health and Human Services, Bureau of Health, Coordinated School Health Program Manager
Aileen Fortune, University of Maine, Cooperative Extension
Susan Gendron, Commissioner, Maine Department of Education

Appendix B
Eating Disorder Workgroup Membership

Laurie Halligan, Maine Governor's Office
Bernie Hershberger, MD, Bowdoin College Health Center
Marcia Homstead, Secretary, Maine State Legislature
Judd Knox, York Hospital
Sharon, Leahy-Lind, Maine Dept. of Health and Human Services, Bureau of Health, Women's Health Consultant
Susan Love, Mainely Girls Board Member
Kathryn Low, Bates College
Karen Marceau, School Nurse
Katie McCoy, LCSW, YWCA of Greater Portland, counselor
Lisa Miller, Bingham Foundation
Karen, O'Rourke, MPH, Maine Center for Public Health Center, Vice President of Operations
Eleanor, Pancoe, University of Maine at Orono, Health Center
Representative Hannah Pingree, Maine Representative
Trish Riley, Maine Office of Health Policy and Finance
Susan Savell, Communities for Children and Youth, Maine Children's Cabinet
Lisa Shields, Maine Commission on Eating Disorders Member
Emily Tornquist, Maine Youth Legislative Advisory Council
Tara Vetrone, former patient
Cindy Visbaras, Health Education Bates College

Appendix C
Survey Methodology

The Treatment Subcommittee created 3 type-specific surveys designed to assess for existing services and programs specific to eating disorder treatment that are provided through mental health and medical care providers, rural and community health centers and hospitals. The afore mentioned groups were selected with the understanding that professionals in these fields, individually or in coordination, would be most likely to have contact with people seeking resources for eating disorders.

Survey questions were developed with the intent to gain knowledge and data about the availability and accessibility of general or specialized programs addressing eating disorders with consideration to location and population served, staff training and professional coordination, the prevalence of consumers presenting for treatment or referral, and providers' willingness to be included on publicized resource lists. Surveys were developed in hard copy form as well as in an on-line version using Surveymonkey.com. Hard copies of the survey are available from the Teen & Young Adult Health Program.

Distribution lists were developed through the combination of mailing lists from sources including list-serves from the Maine Hospital Association, the Maine Academy of Mental Health Services, the Maine Chapter of the American Academy of Pediatrics, the Maine College Health Association, the Department of Professional & Financial Regulation, and other state agencies and programs. A total of 3000 mental health providers and 1600 medical practices from these mailing lists were sent surveys. All 39 hospitals received the survey via the Maine Hospital Association listserve.

Limitations to this survey process and consequently the application of the data include the absence of resources for consultation on survey methodology, design and distribution, low response rate, and the lack of resources such as staff, time and funding.