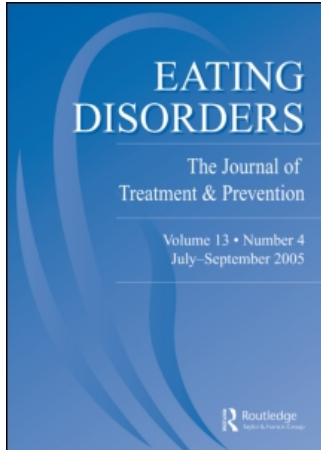


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### Questions & Answers

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## Questions & Answers

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### QUESTION: WHY IS IT IMPORTANT TO ADDRESS EATING DISORDERS THROUGH FEDERAL ADVOCACY?

ANSWER: First, there is a clear need. Millions of people suffer from eating disorders, which have considerable emotional, physical, and financial consequences including high rates of mortality. (Hoek & Van Hoeken, 2003; Keel, et al., 2003). Additionally, there are many issues facing people with eating disorders, their families, professionals, and researchers in the field. One such issue is that treatment is often compromised as health insurance companies provide little coverage for the treatment of eating disorders. This lack of adequate health insurance reimbursement can have enormous consequences for patients, parents, and clinicians alike. Studies suggest shorter hospitalizations for anorectic patients are not cost effective since the majority of patients discharged while still at a low weight are eventually readmitted (Baran, Weltzin, & Kaye, 1995). For example, numbers presented at a Congressional briefing from the Renfrew Centers show that prior to the proliferation of managed care contracts, patients averaged a length of stay of 50 days. In 2001 the average length of stay had dropped to only 15 days. Consequently, the rate of returning patients rose to 33% compared to 10% when more days were reimbursed. Additional research suggests that money saved using shorter and less aggressive treatments may be lost if initial failure to treat the eating disorder results in medical complications down the line (Kaye, Stober, Stein, & Gendall, 1999).

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Second, Congress is not addressing eating disorders. Upon reviewing the online database of congressional activity, the first bill to address eating disorders was introduced in 1987. There were only a total of 17 bills that mentioned eating disorders prior to 1999<sup>1</sup>. This can be compared to other health issues such as diabetes, where 21 bills were introduced in one congressional session referencing diabetes, or cancer, where 62 bills were introduced. Thus diabetes and cancer received more attention in a two-year period than eating disorders had in over 200 years. Furthermore, the only eating disorder bill that ever passed into Public Law was a Congressional Resolution in the Senate in 1989, which designated a National Eating Disorders Awareness Week.

Clearly, federal action on eating disorders was well overdue.

### WHAT IS AN OPTIMAL AVENUE FOR PROMOTING FEDERAL POLICY?

In order to bring policy attention to the issue of eating disorders, it is important to not only capitalize on the power of the individual constituent, but also to expand that power exponentially by creating a coalition of people and organizations (Cogan & Preston, 2002).

Constituents can influence federal policy by voicing their views and concerns to their representatives directly or by joining an advocacy group that works to influence federal policy. Advocating on behalf of a large number of people across the nation adds more political weight to a message than simply advocating on behalf of one's own interests as a constituent (Ceaser, Bessette, O'Toole, & Thurow, 1995). Congressional staff view advocacy groups as key in their efforts to pass sound policies since such groups work with their membership to rally support for a bill to gain active congressional consideration (Cogan & Preston, 2002). Individual groups may further coordinate their efforts by working together through coalitions.

Coalitions are composed of organizations that come together because of common advocacy interests with the aim of developing strength in numbers in order to influence policy. A coalition model increases the opportunities

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<sup>1</sup> Although there were 17 bills, all the bills were simply a recycling of the following 2 bills: (1) **Awareness Week/Day**: to address eating disorders by establishing an eating disorders awareness week or day. This idea was the first eating disorder initiative ever introduced (in 1987) and a version of this idea was introduced as resolution in the 100th, 101st, 102nd, and 105th Congress. It was only passed into Public Law once in 1989, which designated October 23 through October 29, 1989 as Eating Disorders Awareness Week; (2) **Information and Education**: The second bill was first introduced by Representative Slaughter in 1987 to require the Secretary to carry out a program to provide information and education to the public on the prevention and treatment of eating disorders, including the operation of toll-free 24-hour telephone communications. A version of this bill was introduced every year until the language was partly included in the 1998 Committee Report of the DHHS Appropriations Bill. Once the goals of this bill were included in the report language, the Office of Women's Health in the Secretary's Office responded by creating the Body Wise project and including eating disorders in their women's health hotline.

for success, as there are more available constituents to establish personal relationships with members of Congress and their staff in order to bring attention to an issue and advance a policy initiative (Cogan & Preston, 2002).

### WHAT IS THE EATING DISORDERS COALITION FOR RESEARCH, POLICY, & ACTION?

The Eating Disorders Coalition for Research, Policy & Action (EDC), was founded in April 2000 and grew from five founding organizations in 2000 to 25 organizations in only four years. The mission of the EDC is to advance the federal recognition of eating disorders as a public health priority. The Coalition model allowed each organization to maintain its separate and unique identity yet also brought organizations together to address eating disorders at the federal level with a unified voice.

The EDC established the following four policy priorities:

1. Promote the national awareness of eating disorders as a public health problem;
2. Increase resources for research and prevention; enhance training of health professionals;
3. Promote federal support for improved access to care; and
4. Promote initiatives that support the healthy development of children.

### WHAT HAS THE EDC ACCOMPLISHED?

Through advocacy and educational efforts with Members of Congress and their staff the EDC has raised the visibility of eating disorders as an important policy issue. What follows is a highlight of some accomplishments by policy priority.

#### Promote the National Awareness of Eating Disorders as a Public Health Problem

To educate policymakers about the public health problem posed by eating disorders the EDC worked on the bill language of The Eating Disorders Awareness, Prevention, and Education Act of 2003 (H.R. 873), which was introduced in the House of Representatives by Representatives Judy Biggert (Republican from Illinois) and Ted Strickland (Democrat from Ohio). This bill authorizes the use of innovative assistance funds for programs to: (1) improve identification of students with eating disorders; (2) increase awareness of such disorders among parents and students; and (3) train educators with respect to effective eating disorder prevention and assistance methods.

The bill also directs the Secretary of Education to carry out a program to broadcast public service announcements to improve public awareness and to promote the identification and prevention of eating disorders. The EDC really pushed for the bill to include a research component so the last part of the bill requires the National Center for Education Statistics (NCES) and the National Center for Health Statistics (NCHS) to conduct research on the impact eating disorders have on educational advancement and achievement.

Another avenue the EDC used to promote the national awareness of eating disorders was to advocate for the inclusion of an eating disorders relevant objective in Healthy People 2010, which defines the U.S. government's health priorities for the nation. In 2004, the eating disorder objective was almost eliminated from the Healthy People 2010. The EDC was able to work with the researchers in the field to gain data needed to advocate for an eating disorders objective and garner support from federal agency personnel and Congresswoman Louise Slaughter (Democrat-New York), who wrote a letter arguing that an eating disorders objective should remain in the Healthy People 2010 Project. These efforts resulted in a new and improved eating disorders objective.

### Increase Resources for Research and Prevention; Enhance Training of Health Professionals

In order to promote eating disorders research the EDC research committee worked closely with others (such as the AED) to facilitate the appointment of Regina Dolan Sewell, Ph.D., to the position of Eating Disorders (ED) Research Coordinator at the NIMH (a position that is currently held by Regina Smith James, M.D., Chief of Eating Disorders Program). This EDC committee in conjunction with the research community continued to work with NIMH on improving research funding for eating disorders (e.g., a workshop on anorexia in 2002 and a Request for Applications [RFA] on the treatment of anorexia).

To work toward the goal of increased training for health professionals the EDC worked with staff on language for the Improved Nutrition and Physical Activity Act (or the IMPACT Act) (S. 1172) introduced by Senate Majority Leader Bill Frist, MD (Republican-Tennessee) on June 3, 2003. The purpose of the IMPACT Act is to expand an existing grant program for the training of health profession students to include the treatment of overweight, obesity, and eating disorders.

The EDC worked with staffers on the bill and was successful in rewriting it in a way that eating disorders is mentioned *everywhere* that obesity is mentioned. Originally the bill only had language for obesity. By working with Members to include eating disorder language in this bill, Congress recognized eating disorders on par with obesity, which may serve as a precedent for similar initiatives in the future.

### Promote Federal Support for Improved Access to Care

The EDC has advocated for access to care since its inception by supporting mental health parity in health care. In the 107th Congress the EDC advocated for the Paul Wellstone Mental Health Equitable Treatment Act (S. 486) and (H.R. 953), a bill that would prohibit insurance companies from imposing mental health treatment limitations or financial requirements unless comparable limitations and requirements are imposed upon medical-surgical benefits.

### Promote Initiatives that Support the Healthy Development of Children

In order to promote the healthy development of children, the EDC worked with Senator Clinton (D-New York) on the conceptualization and language of the Promoting Healthy Eating Behaviors in Youth Act of 2002. The bill would have provided funding to the Centers for Disease Control and Prevention to award grants to accredited universities or colleges to develop and test educational curricula and intervention programs designed to promote healthy eating behaviors and habits as a means to prevent eating disorders.

## WHAT ARE THE OBSTACLES TO ADVOCACY?

The outlined efforts have been successful in bringing more federal attention to eating disorders. Yet actually passing these bills will take time, effort, and persistence, given that less than 5% of all bills introduced are ever passed into law. Additionally, even good policy can be overrun by politics. A glaring example of this is the mental health parity bill, which in the 2004 Congress had overwhelming support with 56% of House members and 68% of Senators actively supporting the bill, yet still did not pass into law. Many lobbyists agree this is due to the pressures of special interest groups who are preventing the bill from moving forward. Given the nature of advocacy and federal policy it is imperative for organizations such as the EDC to have a presence in Washington, DC and promote policies that could significantly improve the lives of people with eating disorders, their families, professionals, and researchers in the field.

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