



From the CEO

Advocating the Use of the Lived Experience

by E. Clarke Ross, D.P.A.

IN OUR EFFORT to build a social movement, CHADD continues to educate policymakers by emphasizing the lived experience of persons with attention-deficit/hyperactivity disorder (AD/HD) and their families.

I recently was invited to attend a meeting organized by the U.S. Center for Mental Health Services (CMHS) to recommend action steps to meet consumer and family needs related to the Institute of Medicine's (IOM) latest report to improve the quality of health care.

The IOM of the National Academy of Sciences (NAS) has published three significant reports to improve health care quality: *To Err Is Human: Building a Safer Health System*, 2000; *Crossing the Quality Chasm: A New Health System for the 21st Century*, 2001; and *Quality Chasm Series: Improving the Quality of Health Care for Mental and Substance-Use Conditions*, 2005. These reports are available from National Academy Press, and the mental health report is available on the Internet at www.nap.edu/catalog/11470.html.

Use Consumer and Family Preferences and Values

There are nine recommendations to the IOM mental health report, including that the United States should "promote patient-centered care" by supporting "the decision-making abilities and preferences" of persons with mental health conditions and their families.

There are two aims of patient-centered care in the IOM mental health report: (1) clinical care is based on individual consumer and family preferences, needs, values and decision-making and (2) consumers and their families have access to and receive the information necessary to permit well-informed health care decisions. One of CHADD's roles is to educate the American public about science-based treatments. Another role is to provide forums where consumers, families and professionals can share information and views about treatment.

A consistent and small piece of advocating patient-centered care is the National Health Council's (NHC) "Putting Patients First: Patient-Focused Care Initiative." CHADD is one of 49 voluntary health agency members of the NHC. The initiative emphasizes that patients and their families have the ability to obtain and understand science-based information and services.

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NHC hopes that patients and their families manage their health care in partnership with a coordinated health care team that recognizes, respects and acts upon their goals. The first NHC priority is the development of an electronic personal health record (EHR).

Health Care Professionals Must Coordinate Their Care

The fifth recommendation of the IOM mental health report is "to make collaboration and coordination of patient health care services the norm" by "establishing clinically effective linkages." Several years ago, my wife, Beth, took early retirement to better manage the needs of our son, Andrew. She is Andrew's care manager. This is a very frustrating, sometimes draining, and a very time- and detail-intensive activity, even with the benefits of good health insurance and living in a region with excellent professionals. Every consumer and family CHADD member will likely agree with the conclusion of the IOM *Crossing the Quality* report: Multiple clinicians and health care organizations "typically fail to coordinate their care." The IOM states "gaps in care, miscommunication and redundancy" are major sources of patient frustration and suffering. A subsequent IOM report, on behalf of the U.S. Department of Health and Human Services, *Priority Areas for National Attention: Transforming Health Care Quality*, 2003, declared that care coordination is one of the 20 priority health care areas requiring immediate national attention.

CHADD will continue to advocate that consumer and family lived experience become an important part of health care decision making. For this reason, my April 2003 and February 2006 *Attention!*[®] CEO columns focused on enhancing quality of treatment, including respect of the consumer and family lived experience. All previous magazine articles are available on the members-only section of the CHADD Web site. ■