

Expanding Horizons in the New Century: Diversity, Equity, Empowerment
By Patricia L. Harman

Chicago, Illinois served as the backdrop for the 12th Annual CHADD International Conference on diversity, equity and empowerment in the new century. This complex and bustling city is as multi-faceted as the individuals who inhabit it, and both the city and conference offered something for everyone.

Over 2,300 people traveled to the 'Windy City' to learn about the latest innovative practices, assessment and treatment programs, legal issues surrounding AD/HD, teaching strategies for AD/HD children and other educational subjects, as well as issues surrounding co-existing conditions. Educational sessions were geared towards health professionals, educators, adults, college students, legal advocates and parents of children with AD/HD. (Editor's Note: A number of the presentations from the conference will be featured in this and upcoming issues of Attention!.)

The opening plenary session was a celebration of diversity, courage and tenacity in overcoming a variety of challenges. Students from Chicago's All City High School and Youth Chorus opened the session with a collection of spirituals, some classical songs, as well as renditions of several old favorites.

CHADD President, Beth Kaplanek, presented Hall of Fame Awards to three individuals: Xavier Castellanos, M.D., for his outstanding professional achievement in medicine and research on AD/HD, especially in the area of neuroimaging; and Kathleen Nadeau, Ph.D., and Patricia Quinn, M.D. for their professional achievements in educating families and professionals about AD/HD, especially as it relates to girls, women and young adults. 'My mission in grad school was to teach little boys to sit down and be still,' said Nadeau. 'Now my job is to get women to stand up and be heard.' (For a more complete listing of award recipients, please see p.42.)

A panel comprised of Annette Tabor, Lorraine Vasquez, Grace Reina and Evelyn Green, brought the audience to tears as they empathized with these women over the hard-fought struggles with their own AD/HD and/or that of their families. By the same token, they brought the audience to their feet as they recounted the successes they encountered, instilling the hope that despite these difficulties there were triumphs along the way. Each of these women had invested time, effort, energy and tears in overcoming cultural, financial, personal or educational obstacles.

'All I ever wanted for my son was for him to learn how to read,' shared Lorraine Vasquez who described her son as always hyper and 'on the go.' The teachers often tied him into his chairs in order to get him to sit still. On public assistance with limited access to medication and doctors, Vasquez persisted, and today her son attends a private school at the expense of the public school system. 'He is a 13-year-old who reads at a first grade level,' she said, 'but he is excited about school.' Her goal now is to help other parents and families in her community become educated about AD/HD and the services available to them.

At the plenary session the following morning, the Matt Cohen Scholarship Fund was inaugurated for parents who are unable to join CHADD due to financial constraints. 'You should be able to participate fully and equally, regardless of the ability to pay,' said Cohen. The first scholarship was awarded to Lorraine Vasquez.

Peter Jensen, M.D., addressed AD/HD and Bipolar 'What's in a Name? He discussed the components that comprise the diagnosis process:

- structure pathology, (e.g., ulcerative colitis)
- symptoms, (usually subjective in nature as with migraines)
- deviance from the norm, (e.g., hypertension)
- known causes, (e.g., HIV, sickle cell anemia)
- symptoms plus impairment, (e.g., mental disorders)
- cause plus symptom pattern, (e.g., substance abuse psychosis)
- onset, course and/or outcome, and
- other sources.

'All diseases are 'temporary constructions,'" explained Jensen. They are shaped by current norms and values and undergo progressive refinement with scientific advances. He cited treatments for cholera, HIV and peptic ulcers. 'We can sometimes have prevention or intervention before knowing the cause, and the causes are not uniform and may change over time,' he said.

Concerning Bipolar Disorder and AD/HD as co-occurring conditions, Jensen described how some of the symptoms overlap such as over talkativeness, hyperactivity and distractibility. He explained that professionals are still debating what the diagnosis should be called, how it should be treated and how many individuals with other disorders are misdiagnosed.

'There are also definitional-diagnostic challenges,' said Jensen. These involve symptom overlap, the definition of an episode, developmentally sensitive criteria and the fact that while it could be Bipolar Disorder, there is the chance that it is some type of new syndrome altogether.

Jensen also outlined the practical problems in diagnosing individuals with Bipolar Disorder:

Information sources

Ñ Problems with interviewing children under the age of 12,

Whether or not this is a lifetime diagnosis,

The interviewer's expertise, and

Making a diagnosis via symptoms vs. diagnosing through real conversations.

He continued that there are two possible scenarios concerning Bipolar Disorder. First, AD/HD could be an early state of Bipolar Disorder. Second, both AD/HD and Bipolar Disorder are truly present in a child or adult. He also offered the possibility that this

could be a new condition altogether or that it is actually a case of AD/HD plus some new disorder.

Currently, only six studies are being done in this area and according to Jensen there is slight evidence that it is a new syndrome (the combination of AD/HD and Bipolar Disorder), but there are also more questions being raised by these studies. Jensen confirmed that Bipolar Disorder exists in pre-pubertal children and affects one in five AD/HD children. However, he cautioned against applying the Bipolar Disorder label too broadly. He said that treatment included following traditional AD/HD treatments with careful monitoring and the possibility of mood stabilizers if other courses of action or stimulants did not work.

Steven E. Hyman, M.D., director of the National Institute of Mental Health, delivered the closing keynote address. 'Our research needs are urgent,' said Hyman, 'and we are just beginning to understand the most complex object in the history of human science ' the brain.'

He explained that the term 'mental disorders' is archaic and denies any involvement of the brain in these problems. 'There are problems with circuits ' thinking, emotion, behavior ' that are very subtle,' said Hyman. 'It's not like having a stroke or Parkinson's, where many cells are dead, AD/HD and other 'mental illnesses' are disorders of neural communication.'

Concerning research on the brain and behavior as they relate to AD/HD, Hyman said that researchers are looking at the development of attentional mechanisms, emotional control and executive function. 'We need developmentally benchmarked, gold standard diagnostic tests,' he stated.

'We also need to know how attention works in the brain and how it changes throughout life,' continued Hyman. 'We also need to understand gender differences in development, symptoms and treatment response. And we need to look at the impact of experience, illness and treatment on the developing of the nervous system.'

Hyman said that genetics also play an important role in research. 'The discovery of genes will provide the critical tools to understand what goes wrong with the brain.'

There is also a new developmental focus on epidemiology, treatment and prevention at NIMH. This includes: focusing on interactions among AD/HD, mood anxiety and substance use disorders; looking at what happens to AD/HD children as they grow up; and examining the long-term impact of treatment and non-treatment.

Hyman concluded with an overview of public health-oriented research. This encompasses:

Understanding the stigma among children, families, schools and employees,
Improved identification of ongoing risk factors and recognition of mood and anxiety

disorders ' not just disruptive behaviors in schools and primary care settings,
Identifying fiscal and non-fiscal barriers to access,
Overcoming gender and ethnic bias,
Improving practice quality with a shift to chronic disease management modules, and
Improving adherence to treatment.

A new award was created this year to recognize the unique talents and contributions of a particular individual. The 'E' Award was presented to Conference Chair Evelyn Green for her excellence, energy, and her exuberant, enjoyable, effusive, elegant and enlightened leadership and for the example she has demonstrated as the essence of volunteerism in CHADD.

Participation in the live and silent auctions was particularly spirited. Among the items sold were original prints of the award-winning photos from the CHADD photography contest; an Apple computer; a full day's training on education law; several paintings and sculptures; a photo of the late Chicago Bears football player, Walter Payton; a luxury vacation; hand-made custom jewelry; and a variety of gift baskets, books and videos. Prior to the auction, guests were entertained by Karin Tucker and Matthew Stevens.

For those who were unable to attend this year's conference, audiotapes can be purchased by contacting the CHADD office at 301-306-7070.

The 2001 CHADD conference will be held on October 17-20 in Anaheim, California.

Patricia L. Harman is the executive editor of Attention!.