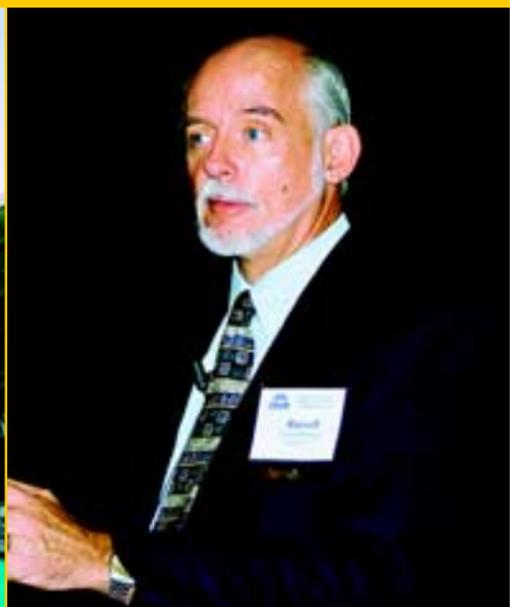




PARTNERS IN PROGRESS: 15 YEARS OF GIVING HOPE, CHANGING LIVES



Highlights from the 14th Annual Conference, October 17–19, 2002, Miami Beach, Florida



by Patricia L. Harman

PROGRESS AND CHANGE were the hallmarks of the 14th Annual CHADD Conference in Miami Beach, Florida. It was a time to look back at the progress that has been made and identify the changes and challenges for the future.

Research, perceptions, diagnostic tools, treatment options, coping mechanisms and information are just some of the areas that have seen the greatest advances in the 100 years since AD/HD was first diagnosed. Even compared to 30 years ago, the progress has been astounding, and yet the need for additional information, training and education has never been more critical.

Over 1500 individuals from around the world attended the conference—some traveling from as far away as Israel, Venezuela, Germany, Japan and England—to learn about the latest treatment advances, research, strategies and tools for treating and managing AD/HD.

A brief retrospective at the opening plenary provided an overview of CHADD's progress, from its inception 15 years ago to its success today. The names and faces of the individuals who have made an impact and played such important roles in the association's growth were chronicled.

The Wraparound Program

Karl Dennis, formally with the community-based program known as Wraparound, provided an overview of the challenges and successes of the program which provides services for hard-to-serve families struggling with the many issues associated with AD/HD. Currently, over 400,000 kids across the country receive some type of wraparound



services. The individuals who started Wraparound adopted the philosophy that they would provide services for everyone who needed them and if the services didn't exist, they would create them. They also believed in the importance of a no punitive discharge policy, meaning a child could not be removed from the program for bad behavior. Another groundbreaking decision involved adjusting the children's treatment and privileges as they progressed instead of moving the kids. This enabled the children to remain in familiar settings with people they knew, and reduced some of the disrup-

tions and changes in their lives. The organizers also sought to provide the services in a family setting—either within the children's own families or in an environment that came as close as possible to being a "family."

"We decided that we would place them in the community, in their own environments," explained Dennis. "We would surround them with staff rather than bricks and mortar, and we discovered that these young people would stay. And if we asked the families what they needed, we discovered that we could keep 83 percent of those kids at home."

Dennis outlined the key elements of a successful program:

- **Services require interagency collaboration.** Need to combine the efforts of mental health services, education services and child welfare.
- **Services should be family focused and driven.** Address the needs of the entire family and involve them in the decision-making process.
- **Services should keep kids in their communities.** Identify and provide the services the families and kids will need to make the program work.
- **Wraparound provides unconditional service.** No matter what they do or how bad it gets, these children still have an option.
- **Base services on students' strengths.** Use their competence in one area to help them in another.
- **Services need to be individualized.** "One size does not fit all."
- **Services need to be culturally competent.** Students need to learn their cultural values and the importance of diversity.
- **Services need to be research driven.** It's important to know sooner rather than later whether a strategy is working. "If we put a plan together and we see improvements, we know it's working," explained Dennis.

This page, Karl Dennis explained the Wraparound program. **Opposite page, (top row)** The exhibit hall featured many products and resources; Conference Chair Janice Bond welcomed guests and attendees; **(middle)** CHADD Hall of Fame Award recipient Arthur L. Robin, Ph.D; The Taste of Miami reception; **(bottom)** Miami Beach's Fontainebleau Hotel; Conference speaker Russell A. Barkley, Ph.D.



Beyond the MTA Study

In his plenary session, Peter Jensen, M.D., provided an overview of the landmark National Institute of Mental Health Multimodal Treatment Study. The study, which started in 1991, followed close to 600 children and is the only clinical trial focusing on the optimal treatments for AD/HD. A diverse sampling of children from a variety of cultural backgrounds, economics and geographic sites was included in the study.

The researchers tested behavioral treatments head to head against medication and found that for most children, medication was a powerful intervention. How the medication was given and monitored also affected its success rate. “We studied what works best,” explained Jensen, “and what we found works best for children with AD/HD is a combination of medication with behavioral interventions.”

The combination of behavioral management with medication also worked well for children in the control group who had oppositional defiant behavior. However, medication was not a substitute for parent training, behavior modification, appropriate educational curricula, appropriate school placement and adequate training skills.

There were other factors that affected the success rate of the children in the study such as parental depression, multiple co-existing conditions and aggression.

On the issue of medication, Jensen said that some of the newer antipsychotic medications that have been found to have lower side effect rates than some of the older ones, and are increasingly prescribed for impulsive/aggressive kids. A new study examining their effectiveness, as well as when to use them and dosing recommendations has been undertaken.

Jensen said that further research needs to be done on AD/HD and co-existing conditions, the medications and treatments needed, as well as new psychotherapies. “We need better treatments for co-morbid subgroups and a better matching of child and family treatments.”

Fears and Prejudices of AD/HD

In the closing plenary session, Tom Brown, Ph.D., spoke about the issues that prevent individuals from getting the treatment they need. “The biggest problem is not the disorder itself, but the ignorance, fears and prejudices that keep suffering children and adults from getting effective treatment,” he explained.

“Fears and prejudices are organized and exploited in the media and by the government,” he continued. “They are also persistent and still widespread among many individuals. This is not a simple or superficial problem.”

Children with AD/HD often grow up with the feeling that there is something fundamentally wrong with them. Their parents feel guilty about not knowing how or not being able to “lighten the load” for them. Many individuals are just relieved to find out that there is a name for what they’ve been feeling and experiencing.

“We’re not talking about a trivial matter,” said Brown. “This disorder causes human suffering in children, adults and families in ways that have powerful effects on their lives.” He said that 7.5 percent of American households are affected by AD/HD.

Realistic Picture of AD/HD

Plenary speakers, Peter Jensen, M.D. (left) and Thomas Brown, Ph.D. (below).

AD/HD is not just a problem of paying attention, it is a complex impairment of the executive functions. Brown described it as an inherited disorder, not due to poor parenting skills or poor schooling. He said the disorder is not related to intelligence and cannot be controlled by willpower or the lack of it. And, while it can be effectively treated in 90 percent of the affected individuals, treatment is not fully effective for all.

Brown identified six clusters and actions of executive functioning that are impaired by AD/HD in children:

Activation—Difficulties getting organized, starting tasks and following directions. Affects:

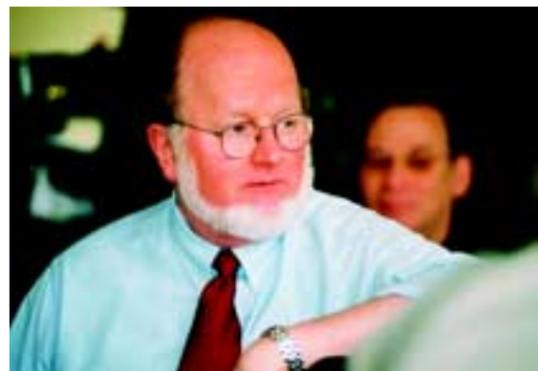
- Organizing
- Prioritizing
- Activating to work

Focus—Difficulties paying attention or excessive daydreaming, grasping main ideas in reading material. Affects:

- Focusing
- Sustaining
- Shifting attention

Effort—Problems with staying alert, needing repeated reminders, chronic underachievement. Affects:

- Regulating alertness
- Sustaining effort
- Processing speed



CHADD AWARD WINNERS

Each year, CHADD presents a number of awards at its Annual Conference to recognize the efforts and contributions that CHADD volunteers and other individuals have made in furthering research on AD/HD, improving the lives of those with the disorder and promoting education about AD/HD.



Above, CHADD President Evelyn Green, M.S.Ed. and Professional Advisory Board member Mark Katz, Ph.D., present CHADD’s 2002 Innovative Program award to Hill Walker, Ph.D. of the First Step to Success program.

CHADD Hall of Fame Award Recipients

Stephen V. Faraone, Ph.D.
William E. Pelham Jr., Ph.D.
Arthur L. Robin, Ph.D.

CHADD Legislative Award

Congressman Patrick J. Kennedy
(Rhode Island)

CHADD 2002 Innovative Program of the Year

First Step to Success: An Early Intervention Program for Reducing Aggressive and Violent Behavior Years Down the Road

CHADD Volunteer Leadership Recipient

Lew Mills, Ph.D., M.F.T.

CHADD Student Research Award
Kevin Fenstermacher, Ph.D.

CHADD Student Research Award—Honorable Mention

Andrea Ridgway



Above, Lew Mills, Ph.D., M.F.T., (center) was the recipient of the 2002 Outstanding Volunteer Leadership award. Barbara Hawkins (left) and Belynda Gauthier (right) also received special recognition awards for their successful volunteer efforts in their chapters.

Emotion—Difficulty experiencing emotion without it taking over. Affects:

- Managing frustration
- Modulating emotions

Memory—The memory function is the “search engine” for the brain. Affects:

- Utilizing working memory
- Accessing recall

Action—Knowing when to speak, when to be quiet, being conscious of how you come across to others. Affects:

- Monitoring and self-regulating action.

Brown said that sometimes professionals stop looking for a problem once they diagnose AD/HD in an individual and they don’t consider that there could be other co-occurring conditions. He also explained that learning disabilities and AD/HD overlap more than people realize. “For kids with learning disabilities, if you are not managing their AD/HD—you’re not addressing the executive function problems. It’s like rearranging the deck furniture on the Titanic.”

Sometimes a disability brings advantages, but usually not until after a child has completed school. Brown identified several businessmen who experienced learning disabilities during their school years, but went on to start companies like Kinko’s, Virgin Airlines and Virgin Records, and Charles Schwab. However, Brown cautioned that risks exist when focusing too heavily on recognizing success stories like these. “While it is heartening to recognize people who make it to the top, there are so many who don’t,” he said. It makes it seem as though anyone with similar problems can make it if they want to, but not everyone can do the impossible.

He also warned of creating excessive pessimism or excessive optimism in our children. “We need to recognize that there are times when some doors will be shut,” said Brown. “And encouraging expectations for an unrealistic goal is delayed cruelty. We set people up to be hurt if we encourage them to believe that wishing for something is the same as getting it.” Instead, he recommends helping children learn to play the cards they’ve been dealt. “It’s not just what you’re

given, but also what you do with it,” he said.

“There are those of us fortunate enough to have someone or the memories of someone who treasured us enough to help us maintain our hope,” he continued. “And love helps to support that hope.” It is a changing and delicate balance with a chronic conflict between pushing our children and easing off of them. Our hopes for our children always exceed reality—but we as parents need to have a realistic picture. “Hope involves the effort to make the best of what is given and what is possible.”

Brown also recognized that parents are limited in their time, attention, affections and resources. Loved ones with AD/HD can demand too much from parents, often needing more than is fair, reasonable or possible from the rest of the family. “Giving too much costs too much,” said Brown, “and giving too little costs too much. We have things we can do for one another—they are not great, but they can be done with great love.” ■

Patricia L. Harman is the editor of *Attention!* magazine.