OVERSIGHT OF THE DEPARTMENT OF EDUCATION AND THE NATIONAL INSTITUTE OF MENTAL HEALTH: CURRENT APPROACHES TO ATTENTION DEFICIT/HYPERACTIVITY DISORDERS

HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS

OF THE

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT HOUSE OF REPRESENTATIVES

ONE HUNDRED FOURTH CONGRESS

SECOND SESSION

JULY 16, 1996

Printed for the use of the Committee on Government Reform and Oversight

U.S. GOVERNMENT PRINTING OFFICE

44-048 WASHINGTON : 1997

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0-16-055847-6

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT

WILLIAM F. CLINGER, JR., Pennsylvania, *Chairman*

BENJAMIN A. GILMAN, New York
DAN BURTON, Indiana
J. DENNIS HASTERT, Illinois
CONSTANCE A. MORELLA, Maryland
CHRISTOPHER SHAYS, Connecticut
STEVEN SCHIFF, New Mexico
ILEANA ROS-LEHTINEN, Florida
WILLIAM H. ZELIFF, JR., New Hampshire
JOHN M. McHUGH, New York
STEPHEN HORN, California
JOHN L. MICA, Florida
PETER BLUTE, Massachusetts
THOMAS M. DAVIS, Virginia
DAVID M. McINTOSH, Indiana
RANDY TATE, Washington
DICK CHRYSLER, Michigan
GIL GUTKNECHT, Minnesota
MARK E. SOUDER, Indiana
WILLIAM J. MARTINI, New Jersey
JOE SCARBOROUGH, Florida
JOHN B. SHADEGG, Arizona
MICHAEL PATRICK FLANAGAN, Illinois
CHARLES F. BASS, New Hampshire
STEVEN C. LATOURETTE, Ohio
MARSHALL "MARK" SANFORD, South Carolina
ROBERT L. EHRLICH, JR., Maryland

CARDISS COLLINS, Illinois
HENRY A. WAXMAN, California
TOM LANTOS, California
ROBERT E. WISE, JR., West Virginia
MAJOR R. OWENS, New York
EDOLPHUS TOWNS, New York
JOHN M. SPRATT, JR., South Carolina
LOUISE McINTOSH SLAUGHTER, New York
PAUL E. KANJORSKI, Pennsylvania
GARY A. CONDIT, California
COLLIN C. PETERSON, Minnesota
KAREN L. THURMAN, Florida
CAROLYN B. MALONEY, New York
THOMAS M. BARRETT, Wisconsin
BARBARA-ROSE COLLINS, Michigan
ELEANOR HOLMES NORTON, District of Columbia
JAMES P. MORAN, Virginia
GENE GREEN, Texas
CARRIE P. MEEK, Florida
CHAKA FATTAH, Pennsylvania
BILL BREWSTER, Oklahoma
TIM HOLDEN, Pennsylvania
ELIJAH E. CUMMINGS, Maryland

BERNARD SANDERS, Vermont (Independent)

JAMES L. CLARKE, *Staff Director*
KEVIN SABO, *General Counsel*
JUDITH McCOY, *Chief Clerk*
BUD MYERS, *Minority Staff Director*

SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS

CHRISTOPHER SHAYS, Connecticut, *Chairman*

MARK E. SOUDER, Indiana
STEVEN SCHIFF, New Mexico
CONSTANCE A. MORELLA, Maryland
THOMAS M. DAVIS, Virginia
DICK CHRYSLER, Michigan
WILLIAM J. MARTINI, New Jersey
JOE SCARBOROUGH, Florida
MARSHALL "MARK" SANFORD, South Carolina

EDOLPHUS TOWNS, New York
TOM LANTOS, California
BERNARD SANDERS, Vermont (Ind.)
THOMAS M. BARRETT, Wisconsin
GENE GREEN, Texas
CHAKA FATTAH, Pennsylvania
HENRY A. WAXMAN, California

EX OFFICIO

WILLIAM F. CLINGER, JR., Pennsylvania
CARDISS COLLINS, Illinois

LAWRENCE J. HALLORAN, *Staff Director and Counsel*
CHRISTOPHER ALLRED, *Professional Staff Member*
THOMAS M. COSTA, *Clerk*
CHERYL PHELPS, *Minority Professional Staff*

CONTENTS

OVERSIGHT OF THE DEPARTMENT OF EDUCATION AND THE NATIONAL INSTITUTE OF MENTAL HEALTH: CURRENT APPROACHES TO ATTENTION DEFICIT/HYPERACTIVITY DISORDERS

TUESDAY, JULY 16, 1996

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HUMAN RESOURCES AND
INTERGOVERNMENTAL RELATIONS,
COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT,
Washington, DC.

The subcommittee met, pursuant to notice, at 2 p.m., in room 311, Cannon House Office Building, Hon. Christopher Shays (chairman of the subcommittee) presiding.

Present: Representatives Shays, Davis, and Barrett.

Staff present: Lawrence J. Halloran, staff director and counsel; Christopher Allred, professional staff member; Thomas M. Costa, clerk; and Cheryl Phelps, minority professional staff member.

Mr. SHAYS. Why can't Johnny sit still? Why can't some children pay attention to the teacher, wait their turn, or remember to bring their books home? What makes some adults unable to hold a job or maintain stable social relationships? With a frequency some say approaches epidemic proportions, the answer to all these questions recently has been: attention deficit/hyperactivity disorder, or ADHD.

ADHD has become the Nation's leading childhood psychiatric disorder. The Department of Education estimates that 3 to 5 percent, or up to 2½ million school-aged children, have ADHD. As measured by growth in the use of methylphenidate, or Ritalin, the most commonly prescribed drug treatment for ADHD, the number of children diagnosed with the disorder has grown two-and-a-half times since 1990. ADHD diagnoses in adults are also increasing dramatically.

These trends have profound implications for health research and education policy. This hearing will examine where we stand with regard to the diagnosis, treatment and educational impacts of ADHD, and where these trends might take us.

Where are we? Despite these trends, significant uncertainty and controversy still surround the proper definition, accurate diagnosis and appropriate treatment of ADHD. Children displaying symptoms of distractibility and impulsiveness were once called hyperkinetic or hyperactive. For awhile, the persistent presence of disruptive symptoms was called minimal brain dysfunction. In 1980,

the diagnosis began to be called attention deficit disorder. Today, it is ADHD, divided into three subtypes, depending on the degree to which hyperactivity accompanies symptoms of inattention and impulsivity.

While there seems to be general agreement that ADHD has physiological causes involving brain chemistry, the lack of an objective test or marker means a diagnosis of ADHD can only be made on the basis of subjective criteria. Subtle judgments must be made about the appropriateness of the child's behavior. Understandably, this has led some to conclude the disorder is overdiagnosed, transforming inferior education, bad parenting or the desire for better academic performance, into a medical problem.

Others believe ADHD is underdiagnosed, particularly in girls, who may be less hyperactive but are almost as likely as boys to suffer from the impulse control and distractibility problems.

There is no cure. Nor is there agreement on effective treatment. Contrary to the prevailing wisdom of just 10 years ago, it now appears fewer than 30 percent of those with ADHD will grow out of the disorder. The use of stimulant drugs can help children and adults focus concentration and restrain impulsive behaviors, but the most effective role of medications in combination with behavioral and other therapies is not yet known.

Yet it is estimated that 70 percent of children diagnosed with ADHD will be given methylphenidate or a similar drug. According to estimates by the National Institute of Mental Health, that means there could be one child in each American classroom who has ADHD and who has taken a powerful drug to treat it.

Trying to bring some clarity to these matters, the Department of Education distributes material to help teachers identify ADHD in the classroom and work with students who have the disorder. The National Institute of Mental Health is conducting extensive research into the causes and treatment of ADHD. We will hear about both efforts today.

We'll also hear from parents of children with ADHD, as well as other experts in dealing with the diagnosis, treatment and education of those whose lives are so profoundly, often painfully, affected by the disorder one perceptive little boy called "my racing brain."

In ADHD, we are trying to draw the line between personality and pathology, and we are placing millions of children and adults on either side of the social, medical, and legal boundary that divides the healthy from the sick. We should do so only with the greatest care, and with a particular reticence to make our children medical patients because, as a culture, we have lost our patience with them.

I welcome all our witnesses today and I look forward to their testimony.

At this time, I would be happy to call on my colleague. Let me mention that at present we don't have a member of the minority, so I'll wait for certain requests of unanimous consent. But I would say to the witnesses that their full testimony will be in the record and they are free to summarize.

At this time, we will call our witnesses. Our first is Dr. Peter Jensen. Our second is Dr. Louis Danielson, and our third is Dr.

Ellen Schiller. If they would please come? And if they are accompanied by anyone, that's welcome, as well. But I want to swear in everyone.

[Witnesses sworn.]

Mr. SHAYS. For the record, I'll note that the witnesses have responded in the affirmative. I apologize up front for the formality of this room. I think this was the committee that had the Un-American Activities Committee in it. And there is no connection to this hearing. You're far away physically, but we're close together in terms of our interest in getting at this issue.

I welcome all of you. I welcome your testimony in the order that I called you. Dr. Jensen, we'll start with you.

STATEMENTS OF PETER JENSEN, CHIEF, CHILD AND ADOLESCENT DISORDERS RESEARCH BRANCH, NATIONAL INSTITUTE OF MENTAL HEALTH; AND LOUIS DANIELSON, DIRECTOR, DIVISION OF INNOVATION AND DEVELOPMENT, OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES, DEPARTMENT OF EDUCATION, ACCOMPANIED BY ELLEN SCHILLER, CHIEF, DIRECTED RESEARCH BRANCH

Dr. JENSEN. Thank you, Mr. Shays, and other members of this distinguished subcommittee. My name is Peter Jensen. And I'm Chief of the Child and Adolescent Disorders Research Branch of the National Institute of Mental Health, part of the NIH.

I'll be testifying today as a research scientist who has been involved in child and adolescent mental disorders research for the past 15 years. In my comments, I'll be drawing upon the wealth of studies that NIH scientists have conducted over the last several decades, actually, as well as several recently completed and ongoing research studies. If we have future chances to meet, I'll look forward to bringing some late breaking findings to this subcommittee's attention.

First of all, what is ADHD? Attention deficit disorder, or ADHD, is a behavioral condition first evident in early childhood. Its core symptoms include developmentally inappropriate levels of activity, distractibility, impulsivity, and especially an inability to sustain attention and concentration. Some persons not well versed in the assessment and diagnosis of mental disorders of children have suggested that ADHD is just normal childhood behavior, but such is definitely not the case. And perhaps in comments later, we can elaborate on that.

How is it diagnosed? The diagnosis is first established by careful clinical determination of the presence of the characteristic symptoms based on these rigorous diagnostic criteria. It cannot be diagnosed, as you point out, Mr. Shays, by any laboratory measure, blood test, or psychological battery, although all of these procedures are very useful to rule out any competing causes of the child's behavioral symptoms.

But, first and foremost, it must be diagnosed by an expert, who is fully versed in the assessment and interviewing of children and their families, and second, can rule out alternative medical and psychological explanations for these symptoms. It shouldn't be diagnosed without such a full evaluation.

What causes ADHD? While the exact cause is not known, it is likely that there are several causes, just as there are multiple causes for pneumonia and hepatitis and other medical conditions. Nonetheless, studies have consistently pointed toward disturbances in brain functioning, particularly in brain areas responsible for attention and memory, areas we call the prefrontal cortex, in particular.

Scientists have documented differences in the size and symmetry of several brain structures in persons with attention deficit disorder. Genetic factors likely play a role in many, though probably not all cases, of ADHD. And it appears to require a combination of both genes that convey susceptibility as well as what we call "second hits" or environmental problems, such as prenatal health care problems, et cetera, that all end up resulting in the characteristic picture of attention deficit hyperactivity disorder.

How is it treated? By far, as Mr. Shays has noted, the most widely studied and clinically effective and commonly prescribed treatments for ADHD are these psycho-stimulants, including dextroamphetamine, methylphenidate or Ritalin as it's commonly known, and pemoline. Now, these treatments are widely regarded in the medical community as the first line psychopharmacologic treatments for ADHD. There are others, however.

These treatments can be truly lifesaving. Numerous studies have demonstrated the short-term efficacy of these medications compared to placebos in dramatically reducing the range of core ADHD symptoms, as well as improving parent-child, parent-teacher, and peer relationships and interactions, as well as improved performance on laboratory and short-term performance on academic tests.

However, the long-term benefits of the use of stimulants, for example, have not been adequately studied. And this is true of most of our medications in the area of the treatment of the behavioral and emotional disorders of children.

The second type of well-established, proven treatments are the behavior therapies, strategies that teach parents, teachers and children, or even sometimes the children themselves, to apply rewards and consequences for on-task, appropriate behaviors versus off-task behaviors.

A good example of this might be the simple "star chart" or "daily report card" that sometimes parents are taught to implement or teachers are taught to implement to help the child manage and regulate his or her behavior. It tracks his or her completion of the goals that have been agreed upon and set by the parent, the teacher, usually in concert with the child.

Now, as with the stimulants, the long-term benefits of the behavioral therapies are also really not known.

Now, basic to sound clinical care is the need to provide treatment that is adapted to the needs of the specific child. What that means is that the treatments, both medical as well as behavioral, have to be targeted to the child's unique needs and integrated across the settings and circumstances of the child's life. So adequate care then demands that not only an accurate diagnostic assessment, but a careful determination of which treatment or which combination of treatments are best for this child.

Unfortunately, this has been an area where we know less than required to provide optimal care. As a result, the NIMH, in partnership with the Department of Education has mounted a six-site study that compares state-of-the-art medication, versus optimal behavior therapies, versus the two treatments in combination, versus the standard clinical care available in the community. This study is the first ever of its type and will help us to determine which treatment truly works best for a given child in the long run. And that becomes a very important consideration as we talk about the treatment of these children.

Why has the diagnosis of ADHD and the prescription of stimulants risen over the last few years? No one disagrees on this account, that the stimulants prescription has risen 3-fold in the last number of years. There are probably four factors that ought to be considered in considering these increases, even though we do not have firm data on the why the increases have taken place.

First of all, there has been increasing interest in eloquence on the part of the parent advocacy groups who have spoken on behalf of these children and their clinical and medical needs.

Second, State departments of education now officially recognize the needs of these children. And they're attempting to provide appropriate resources to them under the provisions of IDEA. We think that this new avenue has certainly led to increased identification and treatment.

Third, managed care can play a role in increasing prescription stimulants. And you've heard from parents and providers alike that sometimes a child is asked by a company to be placed on medication as a precondition to some of the behavioral treatments or psychotherapy under a given health care plan. So this is an important area of concern.

Last, there is extensive anecdotal evidence that some children are diagnosed and treated without an adequate evaluation.

Now, we've recognized the need for better information and what treatments children actually receive and why they receive them.

So NIMH and NIH have mounted a survey of the mental health needs of U.S. children. This will be a survey of 13,000 4- to 17-year-old children in communities throughout the United States to determine what are the mental health needs of U.S. children, how well are they being served, and are there instances in which some children are being underserved; that is, not provided treatments they actually need; or instances where they're actually receiving treatments that are not warranted. And that would get to very much the question of whether ADHD either underdiagnosed or overdiagnosed or potentially undertreated or overtreated.

This study is going in the field in January 1997, this coming year. And definitive evidence and data on these subjects will be available in the summer and fall of next year. So we'll look forward to that.

Last, I would say that the problems of underdiagnosis and overdiagnosis underscore the critical need for training of health care providers. Preliminary studies suggest that clinicians do not conduct adequate assessments in many instances; nor may teachers always recognize the problems. On the one hand, the parent may be blamed for the child's difficulties arising from ADHD and increas-

ing the family's burden of suffering in addition to the child's difficulties.

On the other hand, the diagnosis and medication sometimes may be seen as easy answers to complicated behavioral problems. In this regard, the efforts from the Department of Education to increase teachers' awareness still has been commendable and timely.

Because the NIH has been concerned about the nature of the evidence, the level of the evidence and the level of public concern about the use of stimulants, the diagnosis of attention deficit disorder, and these issues of overdiagnosis and underdiagnosis and overtreatment and undertreatment, the NIH will be conducting a consensus development conference in the fall of 1997. This conference will convene scientific experts to consider all available scientific information, including data from these ongoing studies mentioned above, to determine the degree of consensus regarding the optimal care for ADHD children and the role of stimulant medications in their treatment.

We expect that an important part of our responsibility will then be to disseminate this information to the public concerning what the best scientific data pulled together by impartial experts from around the country and most likely around the world, and then apply that information to the benefit of the health care provision for our children in our U.S. communities. Thank you.

[The prepared statement of Dr. Jensen follows:]

Congressional Testimony, Peter S. Jensen, M.D., July 16, 1996

Thank you Mr. Shays, and other members of this distinguished subcommittee. My name is Peter Jensen, and I am Chief of the Child and Adolescent Disorders Research Branch of the National Institute of Mental Health, part of the National Institutes of Health. I will be testifying today as a research scientist who has been involved in child and adolescent mental disorders research for over 15 years. In my comments I am drawing upon the wealth of studies that NIH scientists have conducted over the last several decades, as well as recently completed and ongoing research. If we have future chances to meet, I would be pleased to bring late-breaking findings to this subcommittee's attention.

What is ADHD? Attention Deficit Hyperactivity Disorder, or ADHD, is a behavioral condition first evident in early childhood. Its core symptoms include developmentally inappropriate levels of activity, distractibility, impulsivity, and especially an inability to sustain attention and concentration. Some persons not well versed in the assessment and diagnosis of mental disorders of children have suggested that ADHD is just normal childhood behavior, but such is definitely *not* the case. Children with ADHD usually suffer from impairing symptoms of the disorder in multiple settings -- in home, at school, and with peers -- characteristically beginning before age 7. These symptoms form a coherent pattern such that well-trained clinicians can reliably diagnose ADHD with a level of accuracy.

How is ADHD Diagnosed? The diagnosis is established by the careful clinical determination of the presence of the characteristic symptoms based on rigorous diagnostic criteria. It *cannot* be diagnosed by any laboratory measure, blood test or psychological battery, although all of these procedures can be useful to rule out any other competing causes of a child's behavioral symptoms. First and foremost, it must be diagnosed by an expert who 1) knows how to assess and interview children and their families, and 2) can rule out alternative medical or psychological explanations for the symptoms. ADHD should not be diagnosed without such a full evaluation.

What "Causes" ADHD? While the exact cause is not known, it is likely that there are several causes, just as there are multiple causes of pneumonia or hepatitis. Nonetheless, studies have consistently pointed towards disturbances in brain functioning, particularly in brain areas responsible for attention and memory. Further, scientists have documented differences in the size and symmetry of several brain structures in persons with ADHD. Genetic factors probably play a role in many though not all cases of ADHD, and it appears to require a combination of genes that convey susceptibility along with certain environmental "second hits" (such as prenatal health problems) to result in the characteristic picture of ADHD.

How Do Children with ADHD Turn Out? Decades of longitudinal studies have shown that 70-80% of afflicted children continue to manifest the syndrome in adolescence and suffer ongoing problems of overactivity, poor school performance, and significant behaviors problems at home and school. Compared to matched control subjects, young adults with ADHD suffer significantly higher levels of impulsivity and restlessness, legal problems, and vocational and marital difficulties. Male adults who had been seen for hyperactivity at a child guidance clinic 25 years earlier are 3-4 times more likely than their brothers to have had problems of nervousness, depression, lack of friends, and poor frustration tolerance in adulthood.

How is ADHD Treated? By far the most widely studied, clinically effective, and commonly prescribed treatments for ADHD are the psychostimulants, including dextroamphetamine, methylphenidate

(Ritalin), and pemoline. These medications are widely regarded in the medical community as the first line psychopharmacologic treatments for ADHD, and can truly be life-saving. Numerous studies have demonstrated the short-term efficacy of the psychostimulants compared to placebos in dramatically reducing a range of core ADHD symptoms, as well as improving parent-child and parent-teacher interactions, problem-solving activities with peers, and performance on laboratory tasks. However, long-term benefits and risks of stimulants have not been adequately studied.

The second type of well-established, proven treatments are the behavior therapies -- strategies that teach parents, teachers, or even sometimes the children themselves to apply rewards and consequences for on-task, appropriate behaviors vs. off-task behaviors. Examples of this may include a simple "star chart" or "daily report card" implemented in home or school that tracks a child's completion of agreed-upon goals. When rigorously implemented, these treatments can profoundly assist a given child to demonstrate increasing control over his/her behavior. However, much of the evidence suggests that these treatments may not be quite as effective as the stimulant medications, can be more difficult or expensive to implement, and may not transfer from one setting to the next. For example, a home-based behavioral program may benefit the child's home behavior, but may not have a meaningful impact on school behavior. As with the stimulants, the long-term benefits of the behavioral therapies are not yet known.

Basic to sound clinical care is the need to provide treatment that is adapted to the needs of a given child. Thus, treatments, both medication and behavioral, should be targeted to meet the child's unique needs and integrated across the settings and circumstances of the child's life. Adequate care demands not only an accurate diagnostic assessment, but a careful determination of *which treatment or combination of treatments are best for this child?* Unfortunately, this has been an area where we know less than required to provide optimal clinical care. As a result, the NIMH in partnership with the Department of Education has mounted a 6-site study that compares 1) state-of-the-art medication, 2) optimal behavior therapies, 3) the two treatments in combination, and 4) standard clinical care available in the child's community. The first-ever of its type, this treatment study has just completed enrollment of nearly 600 children, and will set the treatment standard for ADHD for the next decade. This study will allow us to determine which treatment works best based upon the profile of a given child, as well as help us determine the longer-term outcomes of treatment.

Why has the apparent diagnosis of ADHD and prescription of stimulants risen over the last few years? By all accounts, the diagnosis of ADHD and use of methylphenidate have increased 3-fold in the last few years. These increases in methylphenidate prescribing are not just apparent but real, and found principally in children in the 4-17 year old age-groups. Firm data on ***why*** these increases have occurred are not apparent however, although 3 major factors appear to be responsible. First, there has been increasing interest and eloquence on the part of parent advocacy groups that have spoken on behalf of the need for appropriate care of these children. Second, state departments of education now officially recognize the needs of these children and are attempting to provide appropriate resources to them under the provisions of the Individuals with Disabilities Education Act (IDEA). Undoubtably, this new avenue for children's needs recognition has led to increased identification. Managed care may play a role in the increase in the prescription of stimulants; we have heard from parents and providers alike that some companies ask that a child be placed on medication as a precondition for behavioral treatments or psychotherapy under the health care plan. This is an area of concern. Finally, there is extensive anecdotal evidence that some children are diagnosed and treated without an adequate evaluation.

What ADHD treatments are available and provided in U.S. communities? Recognizing the need for better information on the what treatments children actually receive and why, the National Institute of Mental Health is embarking on a survey of the mental health needs of U.S. children and adolescents. This survey of over 13,000 4 to 17-year-old children will help determine both the number of children with ADHD as well as other behavioral and emotional disorders, and what kinds of treatment these children get. For example, we will learn what proportion of children with ADHD are treated with stimulants versus the behavioral therapies. Further, the problem of under-recognition and under-treatment of mental disorders in children has been a long-standing, vexing problem, and this study will help us determine whether this is still the case with ADHD, or the extent to which some children are being treated with medication when their needs might be better addressed through other alternatives. While the data are not yet in, we suspect (based upon information from smaller-scale studies) that under-diagnosis and over-diagnosis *both* are persisting problems in our communities. Further, it is likely that even when diagnostic assessments are expert and incontrovertible, the clinical, educational, and family resources may be insufficient to provide necessary care for the child. This study will help us learn the extent of the gaps in the care we provide to children with ADHD as well as other conditions.

Information Dissemination. The likely problems of under- and over-diagnosis underscore the critical need for training of health care providers. Preliminary studies indicate that clinicians do not conduct adequate assessments in many instances, nor may teachers always recognize the problem. On the one hand, a parent may be blamed for the child's difficulties arising from ADHD, only increasing the child and family's burden of suffering and increasing the child's difficulties. On the other hand, the diagnosis and medication sometimes may be seen as easy answers to complicated behavioral problems. In this regard the efforts of the Department of Education to increase teachers' awareness and skill has been commendable and timely.

Within the Department of Health and Human Services, substantial efforts are being made to share research information concerning the identification and treatment of children with ADHD. The Secretary recently announced a public health awareness campaign "Communities Together Campaign" designed to increase awareness and treatment of children with behavioral and emotional disorders. For this initiative the National Institute of Mental Health and the Center for Mental Health Services jointly developed information materials and brochures which are being widely distributed in many communities around the country, and additional information is available on the Internet and through fax-back mechanisms. Further, NIMH staff have recently published books on state-of-the-art behavioral treatments for ADHD and other conditions, and scientific journal sections have been devoted to issues concerning optimal medication treatments.

Lastly, the National Institutes of Health recently reviewed information concerning the increases in stimulant prescriptions and the diagnosis of ADHD, and as a consequence, will be conducting a *Consensus Development Conference*. This conference, planned for Fall, 1997, will convene scientific experts to consider all available scientific information (including data from the ongoing studies mentioned above) to determine the degree of consensus concerning optimal care for ADHD children and role of stimulant medications in their treatment. We expect that an important part of our public and professional educational efforts will be in the publication and wide distribution of the results of this consensus conference. Thank you for affording this opportunity to speak on behalf of these children and their research needs.

Mr. SHAYS. Thank you very much, Doctor. Dr. Danielson.

Mr. DANIELSON. Thank you, Mr. Shays, and other members of this distinguished committee. I am Lou Danielson, a psychologist and Director of the Division for Innovation and Development in the Office of Special Ed Programs. The program I direct is a research program within the Office of Special Ed Programs.

I am pleased to testify on behalf of the U.S. Department of Education. I bring to you today a set of research based findings on educating children with attention deficit disorder. In particular, what we learned about educating children with ADD, how we communicated these findings to parents and educators, and what continues to be pressing concerns for the education of children with ADD.

First, what is known about educating children with ADD. In 1991, the Department of Education asked parents and educators: What are the most pressing issues facing the education of children with attention deficit disorder? I might add that this was following the request on the part of Congress in 1990 that we pursue these issues.

They asked us to find the answers to the following questions:

How can children with ADD be appropriately served in the public schools?

How can we obtain a proper diagnosis for children with ADD?

What educational interventions work best?

What are the effects of the medication?

How can the information be communicated to educators, parents, and family members?

To answer these questions, we provided guidance on Federal legislation, synthesized research, and linked with professional and advocacy organizations to communicate the findings.

First, parents asked: How can children with ADD be appropriately served in the public schools?

In a policy memorandum jointly signed by the Assistant Secretaries of the Office of Special Ed and Rehab Services, the Office of Civil Rights, and the Office of Elementary and Secondary Education, the Department of Education clarified that educating children with ADD is the responsibility of both general and special education. Children with ADD may qualify for accommodations or other assistance in general ed settings under section 504 of the 1973 Rehab Act or for special ed and related services under the IDEA.

This policy memorandum was an important clarification, because there had been much confusion about under which circumstances children with ADD could qualify for special education under IDEA or for accommodations under 504.

Second, parents asked: How can we obtain a proper diagnosis for our children? We learned to diagnose a child with ADD requires collaboration and teamwork. Families, teachers, psychologists, and pediatricians must work together as a team to help identify children with ADD. Each member of the team brings critical data regarding the child.

For example, at what age did the behaviors begin to appear? How often do they occur? To what extent do they occur? How are these behaviors affecting academic, emotional, and social outcomes?

Third, educators and parents asked: What interventions work best and what are the effects of medication as a treatment?

We learned from our research synthesis that children with ADD can often be taught effectively in general ed classrooms; medication helps some children with ADD to manage their behavior, but medication alone is not sufficient to ensure that these children learn and achieve at school; all children with ADD need effective educational programs that meet their individual needs. I should emphasize individual.

Such programs integrate the research practices on effective teaching, behavior management, and classroom accommodations.

Fourth, educators and parents asked: How can the answers to our questions be communicated to the professionals and family members who need it?

We undertook a series of communication events. We convened a national forum on meeting educational needs of children with disabilities. We conducted focus groups to guide the development of products. We fostered linkages with national education and parent associations and the media to communicate research based findings on educating children with ADD to educators and parents. I might add that this is unusual for a research organization to communicate in such a thorough and effective way with consumer organizations.

We are undertaking activities to integrate the research-based practices into teacher training programs and to train doctoral students to conduct research on the education of children with attention deficit disorder.

What are the issues today? While answering the critical questions posed by parents and teachers, the Department of Education learned of several areas in which further research on educating children with ADD are needed.

First, what are the most effective educational treatments for children with ADD? Upon our examination of the research, we found that the research is limited in its duration. That is, often children might only be followed for a short period of time to examine the effectiveness of the treatment.

The type of children studied; that is, it might be very young children. We know increasingly that this is a disorder that follows children through their life and very little research is conducted on older students.

And on the settings in which the research was conducted. Much of the research was conducted in clinical settings as opposed to school-based settings.

We are collaborating with the National Institute of Mental Health to conduct a six-site examination of the most effective treatment to help resolve the limitations of the earlier research. Peter talked about this in some detail. This research will inform the appropriate use of medication, with or without an education and family intervention, for achieving better results for children with ADD.

Second, how are children with ADD diagnosed? And how are children with ADD distinguished from children with other learning behavioral problems?

What is the prevalence of children with ADD? We've heard as we did our research ranging estimates of prevalence that ranged from

1 percent up to 10 or 12 percent. There is a great deal of need for research to epidemiological research to really establish what the true prevalence of ADD is. Children with ADD and children with specific brain disease and serious emotional disturbance often share common problems associated with inattention, hyperactivity, and impulsivity. Further investigations need to examine the underlying constructs for defining children with ADD and other co-occurring conditions and examine the prevalence of children with ADD and those who experience these other conditions.

Third, how can complex research-based practices be implemented in the schools? Both research and practice on educating children with ADD requires cooperation among pediatricians, educators, mental health providers, and families for both diagnosis and remediation and education. Future research needs to address how to translate complex research interventions into school based practices.

Again, thank you for this opportunity to share the Department's initiative to synthesize and communicate research-based practices on educating with ADD. I will be happy to answer any questions you may have.

[The prepared statement of Mr. Danielson follows:]

Louis C. Danielson, Ph.D.
Director, Division of Innovation and Development
Office of Special Education and Rehabilitative Services
U.S. Department of Education

Thank you, Mr. Shays and other members of this distinguished committee. I am pleased to testify on behalf of the U.S. Department of Education, Office of Special Education and Rehabilitative Services. I bring to you today, a set of research based findings on educating children with attention deficit disorder. In particular, what we learned about educating children with ADD, how we communicated these findings to parents and educators, and what continues to be pressing concerns for the education of children with ADD.

What is Known About Educating Children with ADD?

In 1991, the Department of Education asked parents and educators: "What are the most pressing issues facing the education of children with attention deficit disorder?" They asked us to find the answers to the following questions.

- how can children with ADD be appropriately served in the public schools?
- how can we obtain a proper diagnosis for children with ADD?
- what educational interventions work the best;
- what are the effects of medication; and
- how can the information be communicated to educators, parents, and family members.

To answer these questions, we provided guidance on federal legislation, synthesized research, and linked with professional and advocacy organizations to communicate the findings.

First, parents asked, "how can children with ADD be appropriately served in the public schools?" In a policy memorandum jointly signed by the Assistant Secretaries in the Office of Special Education and Rehabilitative Services, Office of Civil Rights, and Office of Elementary and Secondary Education, the Department of Education clarified that educating children with ADD is the responsibility of both general and special education. Children with ADD may qualify for accommodations or other assistance in general education settings under Section 504 of the 1973 Rehabilitation Act or for special education and related services under the Individuals with Disabilities Education Act (IDEA).

Second, parents asked, "how can we obtain a proper diagnosis for our children?" We learned to diagnose a child with ADD requires collaboration and teamwork. Families, teachers, psychologists, and pediatricians must work together as a team to help identify children with ADD. Each member of the team brings

critical data regarding the child. For example, at what age did the behaviors begin to appear? How often do they occur? To what extent do they occur? How are these behaviors affecting academic, emotional, and social outcomes?

Third, educators and parents asked, "what educational interventions work best and what are the effects of medication as a treatment?" We learned from our research syntheses that children with ADD can often be taught effectively in general education classrooms; medication helps some children with ADD to manage their behavior, but medication alone is not sufficient to ensure that these children learn and achieve at school; and all children with ADD need effective educational programs that meet their individual needs. Such programs integrate the research practices on effective teaching, behavior management, and classroom accommodations.

Fourth, educators and parents asked, "how can the answers to our questions be communicated to the professionals and family members who need it?" We undertook a series of communication events. We convened a national forum on meeting the educational needs of children with ADD; conducted focus groups to guide the development of the products; fostered linkages with national education and parent associations and the media to communicate the research based findings on educating children with ADD to educators and parents. We are undertaking activities to integrate the research based practices into teacher training programs and to train doctoral students to conduct research on the education of children with ADD.

What are the Issues Today?

While answering the critical questions posed by parents and teachers, the Department of Education learned of several areas in which further research on educating children with ADD are needed.

First, what are the most effective educational treatments for children with ADD? Upon our examination of the research, we found that the research is limited in its duration, the type of children studied, and settings in which the research was conducted. We are collaborating with the National Institute of Mental Health to conduct a six site examination of the most effective treatment to help resolve the limitations of the earlier research and to answer this critical question. This research will inform the appropriate use of medication, with or without an education and family intervention, for achieving better results for children with ADD. This research needs to follow the children to determine the long-term results of the intervention.

Second, how are children with ADD diagnosed and how are children with ADD distinguished from children with other learning and behavioral problems? What is the prevalence of children with ADD? Children with ADD and children with specific learning

disability and serious emotional disturbance often share common problems associated with inattention, hyperactivity, and impulsivity. Further investigations should examine the underlying constructs for defining children with ADD and other co-occurring conditions and examine the prevalence of children with ADD and those who experience co-occurring conditions.

Third, how can complex research based practices be implemented in the schools. Both research and practice on educating children with ADD requires cooperation among pediatricians, educators, mental health providers and families - both for diagnosis and education. Future research needs to address how to translate complex research interventions into school based practices.

Again, thank you for this opportunity to share the Department's initiative to synthesize and communicate research based practices on educating children with ADD. I will be happy to answer any questions you may have.

UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

THE ASSISTANT SECRETARY

MEMORANDUM SEP 16 1994

DATE :

TO : Chief State School Officers

FROM : Robert R. Davila
Assistant Secretary
Office of Special Education
and Rehabilitative Services

Michael L. Williams
Assistant Secretary
Office for Civil Rights

John T. MacDonald
Assistant Secretary
Office of Elementary
and Secondary Education

SUBJECT: Clarification of Policy to Address the Needs of Children with Attention Deficit Disorders within General and/or Special Education

I. Introduction

There is a growing awareness in the education community that attention deficit disorder (ADD) and attention deficit hyperactive disorder (ADHD) can result in significant learning problems for children with those conditions.[1] While estimates of the prevalence of ADD vary widely, we believe that three to five percent of school-aged children may have significant educational problems related to this disorder. Because ADD has broad implications for education as a whole, the Department believes it should clarify State and local responsibility under Federal law for addressing the needs of children with ADD in the schools. Ensuring that these students are able to reach their fullest potential is an inherent part of the National education goals and AMERICA 2000. The National goals, and the strategy for achieving them, are based on the assumptions that: (1) all children can learn and benefit from their education; and (2) the educational community must work to improve the learning opportunities for all children.

---

[1] While we recognize that the disorders ADD and ADHD vary, the term ADD is being used to encompass children with both disorders.

This memorandum clarifies the circumstances under which children with ADD are eligible for special education services under Part B of the Individuals with Disabilities Education Act (Part B), as well as the Part B requirements for evaluation of such children's unique educational needs. This memorandum will also clarify the responsibility of State and local educational agencies (SEAs and LEAs) to provide special education and related services to eligible children with ADD under Part B. Finally, this memorandum clarifies the responsibilities of LEAs to provide regular or special education and related aids and services to those children with ADD who are not eligible under Part B, but who fall within the definition of "handicapped person" under Section 504 of the Rehabilitation Act of 1973. Because of the overall educational responsibility to provide services for these children, it is important that general and special education coordinate their efforts.

II. Eligibility for Special Education and Related Services under Part B

Last year during the reauthorization of the Education of the Handicapped Act [now the Individuals with Disabilities Education Act], Congress gave serious consideration to including ADD in the definition of "children with disabilities" in the statute. The Department took the position that ADD does not need to be added as a separate disability category in the statutory definition since children with ADD who require special education and related services can meet the eligibility criteria for services under Part B. This continues to be the Department's position.

No change with respect to ADD was made by Congress in the statutory definition of "children with disabilities;" however, language was included in Section 102(a) of the Education of the Handicapped Act Amendments of 1990 that required the Secretary to issue a Notice of Inquiry (NOI) soliciting public comment on special education for children with ADD under Part B. In response to the NOI (published November 29, 1990 in the Federal Register), the Department received over 2000 written comments, which have been transmitted to the Congress. Our review of these written comments indicates that there is confusion in the field regarding the extent to which children with ADD may be served in special education programs conducted under Part B.

A. Description of Part B

Part B requires SEAs and LEAs to make a free appropriate public education (FAPE) available to all eligible children with disabilities and to ensure that the rights and protections of Part B are extended to those children and their parents. 20 U.S.C. 1412(2); 34 CFR §§300.121 and 300.2. Under Part B, FAPE, among other elements, includes the provision of special education and related services, at no cost to parents, in

conformity with an individualized education program (IEP). 34 CFR §300.4.

In order to be eligible under Part B, a child must be evaluated in accordance with 34 CFR §§300.530-300.534 as having one or more specified physical or mental impairments, and must be found to require special education and related services by reason of one or more of these impairments.[2] 20 U.S.C. 1401(a)(1); 34 CFR §300.5. SEAs and LEAs must ensure that children with ADD who are determined eligible for services under Part B receive special education and related services designed to meet their unique needs, including special education and related services needs arising from the ADD. A full continuum of placement alternatives, including the regular classroom, must be available for providing special education and related services required in the IEP.

B. Eligibility for Part B services under the "Other Health Impaired" Category

The list of chronic or acute health problems included within the definition of "other health impaired" in the Part B regulations is not exhaustive. The term "other health impaired" includes chronic or acute impairments that result in limited alertness, which adversely affects educational performance. Thus, children with ADD should be classified as eligible for services under the "other health impaired" category in instances where the ADD is a chronic or acute health problem that results in limited alertness, which adversely affects educational performance. In other words, children with ADD, where the ADD is a chronic or acute health problem resulting in limited alertness, may be considered disabled under Part B solely on the basis of this disorder within the "other health impaired" category in situations where special education and related services are needed because of the ADD.

C. Eligibility for Part B services under Other Disability Categories

Children with ADD are also eligible for services under Part B if the children satisfy the criteria applicable to other disability categories. For example, children with ADD are also eligible for services under the "specific learning disability" category of

---

[2] The Part B regulations define 11 specified disabilities. 34 CFR §300.5(b)(1)-(11). The Education of the Handicapped Act Amendments of 1990 amended the Individuals with Disabilities Education Act [formerly the Education of the Handicapped Act] to specify that autism and traumatic brain injury are separate disability categories. See section 602(a)(1) of the Act, to be codified at 20 U.S.C. 1401(a)(1).

Part B if they meet the criteria stated in §§300.5(b)(9) and 300.541 or under the "seriously emotionally disturbed" category of Part B if they meet the criteria stated in §300.5(b)(8).

III. Evaluations under Part B

A. Requirements

SEAs and LEAs have an affirmative obligation to evaluate a child who is suspected of having a disability to determine the child's need for special education and related services. Under Part B, SEAs and LEAs are required to have procedures for locating, identifying and evaluating all children who have a disability or are suspected of having a disability and are in need of special education and related services. 34 CFR §§300.128 and 300.220. This responsibility, known as "child find," is applicable to all children from birth through 21, regardless of the severity of their disability.

Consistent with this responsibility and the obligation to make FAPE available to all eligible children with disabilities, SEAs and LEAs must ensure that evaluations of children who are suspected of needing special education and related services are conducted without undue delay. 20 U.S.C. 1412(2). Because of its responsibility resulting from the FAPE and child find requirements of Part B, an LEA may not refuse to evaluate the possible need for special education and related services of a child with a prior medical diagnosis of ADD solely by reason of that medical diagnosis. However, a medical diagnosis of ADD alone is not sufficient to render a child eligible for services under Part B.

Under Part B, before any action is taken with respect to the initial placement of a child with a disability in a program providing special education and related services, "a full and individual evaluation of the child's educational needs must be conducted in accordance with requirements of §300.532." 34 CFR §300.531. Section 300.532(a) requires that a child's evaluation must be conducted by a multidisciplinary team, including at least one teacher or other specialist with knowledge in the area of suspected disability.

B. Disagreements over Evaluations

Any proposal or refusal of an agency to initiate or change the identification, evaluation, or educational placement of the child, or the provision of FAPE to the child is subject to the

written prior notice requirements of 34 CFR §§300.504-300.505.[3] If a parent disagrees with the LEA's refusal to evaluate a child or the LEA's evaluation and determination that a child does not have a disability for which the child is eligible for services under Part B, the parent may request a due process hearing pursuant to 34 CFR §§300.506-300.513 of the Part B regulations.

IV. Obligations Under Section 504 of SEAs and LEAs to Children with ADD Found Not To Require Special Education and Related Services under Part B

Even if a child with ADD is found not to be eligible for services under Part B, the requirements of Section 504 of the Rehabilitation Act of 1973 (Section 504) and its implementing regulation at 34 CFR Part 104 may be applicable. Section 504 prohibits discrimination on the basis of handicap by recipients of Federal funds. Since Section 504 is a civil rights law, rather than a funding law, its requirements are framed in different terms than those of Part B. While the Section 504 regulation was written with an eye to consistency with Part B, it is more general, and there are some differences arising from the differing natures of the two laws. For instance, the protections of Section 504 extend to some children who do not fall within the disability categories specified in Part B.

A. Definition

Section 504 requires every recipient that operates a public elementary or secondary education program to address the needs of children who are considered "handicapped persons" under Section

---

[3] Section 300.505 of the Part B regulations sets out the elements that must be contained in the prior written notice to parents:

> (1) A full explanation of all of the procedural safeguards available to the parents under Subpart E;
> (2) A description of the action proposed or refused by the agency, an explanation of why the agency proposes or refuses to take the action, and a description of any options the agency considered and the reasons why those options were rejected;
> (3) A description of each evaluation procedure, test, record, or report the agency uses as a basis for the proposal or refusal; and
> (4) A description of any other factors which are relevant to the agency's proposal or refusal.

34 CFR §300.505(a)(1)-(4).

504 as adequately as the needs of nonhandicapped persons are met. "Handicapped person" is defined in the Section 504 regulation as any person who has a physical or mental impairment which substantially limits a major life activity (e.g., learning). 34 CFR §104.3(j). Thus, depending on the severity of their condition, children with ADD may fit within that definition.

B. Programs and Services Under Section 504

Under Section 504, an LEA must provide a free appropriate public education to each qualified handicapped child. A free appropriate public education, under Section 504, consists of regular or special education and related aids and services that are designed to meet the individual student's needs and based on adherence to the regulatory requirements on educational setting, evaluation, placement, and procedural safeguards. 34 CFR §§104.33, 104.34, 104.35, and 104.36. A student may be handicapped within the meaning of Section 504, and therefore entitled to regular or special education and related aids and services under the Section 504 regulation, even though the student may not be eligible for special education and related services under Part B.

Under Section 504, if parents believe that their child is handicapped by ADD, the LEA must evaluate the child to determine whether he or she is handicapped as defined by Section 504. If an LEA determines that a child is not handicapped under Section 504, the parent has the right to contest that determination. If the child is determined to be handicapped under Section 504, the LEA must make an individualized determination of the child's educational needs for regular or special education or related aids and services. 34 CFR §104.35. For children determined to be handicapped under Section 504, implementation of an individualized education program developed in accordance with Part B, although not required, is one means of meeting the free appropriate public education requirements of Section 504.[4] The child's education must be provided in the regular education classroom unless it is demonstrated that education in the regular environment with the use of supplementary aids and services cannot be achieved satisfactorily. 34 CFR §104.34.

Should it be determined that the child with ADD is handicapped for purposes of Section 504 and needs only adjustments in the regular classroom, rather than special education, those adjustments are required by Section 504. A range of strategies is available to meet the educational needs of children with ADD.

---

[4]Many LEAs use the same process for determining the needs of students under Section 504 that they use for implementing Part B.

Regular classroom teachers are important in identifying the appropriate educational adaptions and interventions for many children with ADD.

SEAs and LEAs should take the necessary steps to promote coordination between special and regular education programs. Steps also should be taken to train regular education teachers and other personnel to develop their awareness about ADD and its manifestations and the adaptations that can be implemented in regular education programs to address the instructional needs of these children. Examples of adaptations in regular education programs could include the following:

> providing a structured learning environment; repeating and simplifying instructions about in-class and homework assignments; supplementing verbal instructions with visual instructions; using behavioral management techniques; adjusting class schedules; modifying test delivery; using tape recorders, computer-aided instruction, and other audio-visual equipment; selecting modified textbooks or workbooks; and tailoring homework assignments.

Other provisions range from consultation to special resources and may include reducing class size; use of one-on-one tutorials; classroom aides and note takers; involvement of a "services coordinator" to oversee implementation of special programs and services, and possible modification of nonacademic times such as lunchroom, recess, and physical education.

Through the use of appropriate adaptations and interventions in regular classes, many of which may be required by Section 504, the Department believes that LEAs will be able to effectively address the instructional needs of many children with ADD.

c. **Procedural Safeguards Under Section 504**

Procedural safeguards under the Section 504 regulation are stated more generally than in Part B. The Section 504 regulation requires the LEA to make available a system of procedural safeguards that permits parents to challenge actions regarding the identification, evaluation, or educational placement of their handicapped child whom they believe needs special education or related services. 34 CFR §104.36. The Section 504 regulation requires that the system of procedural safeguards include notice, an opportunity for the parents or guardian to examine relevant records, an impartial hearing with opportunity for participation by the parents or guardian and representation by counsel, and a

review procedure. Compliance with procedural safeguards of Part B is one means of fulfilling the Section 504 requirement.[6] However, in an impartial due process hearing raising issues under the Section 504 regulation, the impartial hearing officer must make a determination based upon that regulation.

V. Conclusion

Congress and the Department have recognized the need to provide information and assistance to teachers, administrators, parents and other interested persons regarding the identification, evaluation, and instructional needs of children with ADD. The Department has formed a work group to explore strategies across principal offices to address this issue. The work group also plans to identify some ways that the Department can work with the education associations to cooperatively consider the programs and services needed by children with ADD across special and regular education.

In fiscal year 1991, the Congress appropriated funds for the Department to synthesize and disseminate current knowledge related to ADD. Four centers will be established in Fall, 1991 to analyze and synthesize the current research literature on ADD relating to identification, assessment, and interventions. Research syntheses will be prepared in formats suitable for educators, parents and researchers. Existing clearinghouses and networks, as well as Federal, State and local organizations will be utilized to disseminate these research syntheses to parents, educators and administrators, and other interested persons.

In addition, the Federal Resource Center will work with SEAs and the six regional resource centers authorized under the Individuals with Disabilities Education Act to identify effective identification and assessment procedures, as well as intervention strategies being implemented across the country for children with ADD. A document describing current practice will be developed and disseminated to parents, educators and administrators, and other interested persons through the regional resource centers network, as well as by parent training centers, other parent and consumer organizations, and professional organizations. Also, the Office for Civil Rights' ten regional offices stand ready to provide technical assistance to parents and educators.

It is our hope that the above information will be of assistance to your State as you plan for the needs of children with ADD who require special education and related services under Part B, as well as for the needs of the broader group of children with ADD

---

[6]Again, many LEAs and some SEAs are conserving time and resources by using the same due process procedures for resolving disputes under both laws.

who do not qualify for special education and related services under Part B, but for whom special education or adaptations in regular education programs are needed. If you any questions, please contact Jean Peelen, Office for Civil Rights; (Phone: 202/732-1635), Judy Schrag, Office of Special Education Programs (Phone: 202/732-1007); or Dan Bonner, Office of Elementary and Secondary Education (Phone: 202/401-0984).

Mr. SHAYS. Thank you, Dr. Danielson. We'll start our questions with Mr. Davis.

Mr. DAVIS. Why don't we read more about attention deficit disorder? I mean, the exact cause of the disorder really seems to be unknown. This is something that in all public school systems parents try to get their kids diagnosed here because you get, of course, extra—you get extra attention in the class, extra resources put into it that you wouldn't otherwise. There is a great deal of cynicism about going out to the right expert to get your child examined. It would help if there was some exact test or we knew what caused the disorder, but we don't seem to.

While scientists have documented differences in the size and the symmetry of several brain structures in persons with ADHD, there is still, at least as far as I can tell, no biological indicator that can be used to make the diagnosis.

Any thoughts on that?

Dr. JENSEN. Yes, sir. Well, in terms of the cause and why we still don't know the cause, it's very likely that there are multiple causes. And as with any complex medical condition, whether it be diabetes which is likely to have several causes or hypertension, also likely to have several causes, the same applies here.

With children, however, we have to proceed cautiously with research that looks at the underlying etiologies, whether it be the way the brain works or the way that sugar is taken up in the brain, because some of the research procedures expose children to, for example, ionizing radiation. So research has to proceed cautiously to the extent that it's both appropriate and the risks are outweighed by potential benefits resulting from the study.

What I can say is there is good clarity that there are clear differences in the areas of prefrontal cortex functioning across most of the studies in children with attention deficit disorder. And while that boils down to our ability to discriminate groups of ADHD children, it doesn't let us come up with a single definitive diagnostic test for the given child.

So we can say, yes, biologic mechanisms are at work and we can through our research implicate perinatal trauma, and the likely effects of genes. But it will probably be another 5 to 10 years before we'll be able to define these subgroups more definitively to come up with specific causes for subgroups.

I should point out that this is very much the same situation as with schizophrenia, where there is no marker for schizophrenia. There is no blood test for schizophrenia, major depressive disorder, or bipolar disorder. All of these disorders of brain functioning and structure are our most complex biomedical diseases. And we are just getting more tools on-line to help us isolate the subgroups and come up with the definitive types. And eventually we'll be able to look at the constellation of genes and environmental exposures that will help us to understand the given child.

So what you want is very much what we are hoping to get toward. We're just not there quite yet.

Mr. DAVIS. Dr. Danielson, do you want to elaborate on that or make any comment on that? I have another question for you, if you don't want to say anything.

Mr. DANIELSON. Yes. Well, I think from my perspective, I think what's important is the diagnosis relies to a high degree upon the behavior of the child, the fact that it's observed in multiple settings, that it existed over a long period of time. So I think there is—this is very important, I think, from a school perspective, because the school intervention is one that's primarily going to focus on those very behaviors that we observe in children, that are diagnosed with ADD.

Dr. JENSEN. Mr. Davis, can I add to that?

Mr. DAVIS. Please.

Dr. JENSEN. I think that was a terrific response. The pattern of the symptoms and the fact that they occur across home and school settings beginning at an early age and forming a characteristic cluster of signs and symptoms have resulted that when you do actual tests of the reliability of the diagnosis, reliabilities are in the range of 0.8 and 0.9. Now, in medical terminologies, that's terrific. And that's higher than actually we can do when we make the diagnosis of hypertension. So the reliability of the diagnosis is quite remarkable in the hands of an expert who knows how to do the assessment.

Mr. DAVIS. Let me ask, Dr. Danielson, the Department's efforts to help schools and teachers understand the disorders that have been made, primarily they've been focused on the elementary school age. That's where you get usually early diagnosis.

What actions do you take to improve the identification and treatment in secondary grades? Because we're going to hear some testimony today from some parents whose children were not diagnosed until they were into high school. And, sometimes, frankly, you can get through elementary school without a lot of attention in some school systems. Any thoughts on that?

Mr. DANIELSON. Our effort, as I mentioned, was to synthesize a body of research and to disseminate a body of research. And I think that one of the problems we identified is that there's not much of a body of research that focuses on older students with attention deficit disorder. And so I would say that's one of the issues that we need to address: to conduct some of that research on students that are at the junior high, high school level, to look at interventions.

I might add that this is not—it's a problem that I would say is also true in some of the other disability areas where we know somewhat less about effective secondary school programming. And the research that we're supporting, at Office of Special Ed Programs, is trying very much to address some of the knowledge gap that exists at the secondary school level. We recently conducted a national longitudinal transition study looking at secondary school experiences of children with disabilities and then followed them both through their high school program and then into the first few years post-adulthood.

And we found that for many of these youth with disabilities at the secondary school level, they often did not have some of the supplemental aids and services, the accommodations in their program that they might require. Even though the sample didn't include children with attention deficit disorder, I would expect—and I'm not surprised by the observation you pointed out, that there are

some—that there are a lack of availability of accommodations at the secondary school level.

Mr. SHAYS. Mr. Barrett.

Mr. BARRETT. Thank you, Mr. Chairman. I want to thank you for convening these hearings. I think it's important that we have these hearings.

Dr. Jensen, one of the more interesting comments that I saw in your testimony is the comment that managed care may play a role in the increase in the prescription for stimulants.

Can you elaborate on that for me, please?

Dr. JENSEN. Yes. Certainly, health care reform has taken place over the last number of years as increasing specifications on access and sometimes, limitations on access to care has been required as a part of providing some capitation to the costs of mental health care, as well as other forms of care.

We've heard anecdotally from parents that under certain circumstances, it's difficult for them to get full access to the range of behavioral therapies or psychological therapies, and that sometimes a stimulant medication may be a precondition or that the reviewer will want to see that the whole range of therapies are on line as a part of providing additional behavioral therapies.

We don't know definitively to what extent this is actually occurring. And this is really anecdotal. As we go into the field with this large-scale survey next year, we will better identify children who have the diagnosis of attention deficit disorder, what kinds of managed care and health care access provisions do they have and what kind of care they're receiving as a function of both their diagnostic difficulties, as well as their insurance coverage.

Mr. BARRETT. Do you think we should be taking steps or steps should be taken to ensure that this does not happen? Do you think it's appropriate to have a prescription as a condition in order to get some sort of diagnosis or treatment?

Dr. JENSEN. Well, the critical thing is, will each child's care be individualized? So to the extent that someone who does not know the child and has not assessed a given child's difficulties is mandating a certain way of proceeding that is not research-based and established by standards of evidence, is inappropriate.

So to the extent that anyone interferes with this relationship between the best medical practices and treatment tailored to a given child, this is inappropriate and it should be an important concern. Whether this is happening is another issue and the extent that it is happening, but certainly we've heard this concern registered in a number of settings.

Mr. BARRETT. Dr. Danielson, what are your views on that?

Mr. DANIELSON. Well, I certainly agree with what Peter laid out. And, of course, one of the underlying principles of IDEA is this concept of individualization. That it's a kid by kid process for identifying the needs and for implementing the program. So, clearly, some careful assessment of the child should be the basis for whether it's medication or whether it's the educational intervention should be the basis of the intervention.

Mr. BARRETT. Dr. Danielson, continuing with you, one of the concerns that has been raised to me is the diagnosis of ADHD may become a sort of catch-all diagnosis; in particular, for minority stu-

dents, that they might be classified as this. What steps is the Department taking to make sure that this does not happen?

Mr. DANIELSON. Well, I should say first that I don't know that we have any evidence at this point that it is a problem with ADHD, that is, over-representation of minority students. Although given that in certain other categories of disability, that this has been an issue, I think it's very smart to be concerned about that.

I think, if anything, part of our problem on the data side is that we don't currently have a lot of information about the number of students that are served by schools under the category of ADHD, nor do we have any data on the—on gender or race ethnicity for that category.

But on the issue of steps that should be taken, we have for the last couple of years been very concerned about this issue and have—we've done a review of the literature about what some of the most effective strategies are that exist to address this issue. We've been working with the Office for Civil Rights, who, as you may know, also enforces a companion piece of legislation and is also concerned about this issue, to develop some technical assistance materials that can be used as a part of enforcement strategy. So that when they identify problems occurring in district, it isn't kind of just going in and kind of beating on a district. That they have something that they can offer to the district, some proven strategies for addressing this issue.

So we've been working to disseminate some of that information, as well.

Mr. BARRETT. Dr. Jensen.

Dr. JENSEN. Yes. We did conduct some small-scale studies and looked at the issue of the potential for disproportionate identification of children with attention deficit disorder among various communities, including the minority communities with minority children, et cetera. And the data at this point do not support that this indeed is the case. Now, definitive evidence will follow next year when we actually move into this large scale U.S.-wide survey of some 13,000 children.

It is of interest and should be noted that in one of the various medication data bases that have tapped the number of children who receive medication—a proprietary data base maintained by a private company for the pharmaceutical industry—that data suggests actually that minority children disproportionately underutilize stimulants, medication, and are undertreated compared to the larger population from which they're drawn.

So we know this is an important area of concern. The data don't support the actual disproportionate identification or overtreatment in the minority community as a problem.

Mr. BARRETT. Let me make sure I understand. You're saying that minority children may be diagnosed, but may not be receiving the stimulants? Or they're not being diagnosed, or both?

Dr. JENSEN. Both. Probably some are less likely to be diagnosed and some are less likely to receive stimulants. Now, this is not representative data across the entire United States, but it is based on one of the largest proprietary data bases that have been available. And one of the later commentators, Dr. Swanson, who actually con-

ducted some of this research might comment on this, since that's really his data.

Mr. BARRETT. And, clearly, one of the most controversial components of this debate is the overprescription issue or underprescription issue, however you want to frame it. My understanding is there may even be some divisions between the Drug Enforcement Agency, some of the education establishment, the drug manufacturers, as to whether methylphenidate or more commonly Ritalin are being overprescribed. What's your read on why the United States completely dominates this market?

Dr. JENSEN. Well, there are a number of factors. First and most importantly is I think we have done a much better job in the last 3 or 4 years to decrease stigma, to break down some of the barriers and the problems to access care for many of these children. So many more children are being identified.

Now, any time a significant new piece of information emerges—in this case, decreased stigma and greater awareness of the brain-behavior relationships in children with attention deficit disorder, the potential for overdiagnosis and overtreatment is always a possibility, as we've been learning recently with antibiotics, for example. And it's causing some concerns.

So as new tools are available and new information is available, there is always the danger of some misuse.

In a number of countries—I returned recently from an international meeting of child psychiatrists—many of them lament the fact that these medications, which they see as extremely effective, are unavailable in their countries. And so many of these children in other countries really end up failing in school systems or are shuttled off into trade schools, despite greater abilities in many of these children, or end up in the criminal justice system because of a pathway toward increasing problems.

So if you talk to other countries in terms of the clinicians, they'll tell you, this is not a good thing.

Mr. BARRETT. If I could interrupt? We hear so much about how drugs that are good drugs are available in other countries. If this is a good drug, why is it not available in other countries; yet, it is available here? What's happening in those other countries that prevent it from becoming widely used there?

Dr. JENSEN. I can't comment on the drug regulation practices in other countries, but certainly we often get medications last because FDA has very elaborate and I think appropriate series of steps before medications can go on the market after testing for safety and efficacy. And those provisions aren't quite as strict in other countries.

Where the attitudinal issues within terms of drug control procedures and drug enforcement agencies in other countries is really unclear to me. But it's clear that the United States, if you will, has been more open toward an empirically-based strategy: if it helps a child and it can be shown to be safe and effective, then it ought to be available as a treatment alternative.

And I think attitudinal issues have prevented its broader use.

And there is a known data base, I should point out, that it is not based on scientific evidence that the doors are shut in other countries.

Mr. BARRETT. And one final question, if I could, Mr. Chairman. Dr. Danielson, in your testimony, you made reference to the IDEA legislation. As you probably know, that's passed the House and its prospects are somewhat cloudy in the Senate right now.

In your view, what impact has that legislation had and what would be impact if that legislation is not reauthorized?

Mr. DANIELSON. Well, as you probably know, the part B provision of the legislation is permanent. But, of course, there are some provisions to the part B legislation that the House bill would amend that are actually quite consistent with the administration's bill. I think they're important for children with attention deficit disorder.

While the bill would not—in my view, would not expand the eligibility, which certainly potentially is an issue, that who is eligible would, I believe, largely stay the same under the House bill as under current legislation.

The one area that the bill, I think, addresses, Mr. Davis raised the issue a moment ago about secondary school programmings and the fact that someone later is going to testify about the concerns about services not kind of following through at the secondary school level.

And one of the things that the bill would deal with is access to the general ed curriculum. And also in the IP provisions, the individualized education program plan provisions, it would require that IP's identify the supplemental aids and services that children need.

And I should point out that that was one of the things that we found in our longitudinal study of secondary school students. That many of them don't have—particularly if they're spending the bulk of their time in the regular classroom, they often don't have the supplemental aids and services identified that they need to succeed in that classroom. And most kids with ADD are going to be in that regular classroom and are going to need some supplemental aids and services.

And I think that the legislation that passed in the House would be very helpful to address the issue that Mr. Davis pointed out. So, I think it would be very unfortunate if that were not to pass, because we would—it would still be then current law that would exist.

Mr. BARRETT. Thank you very much, Mr. Chairman.

Mr. SHAYS. Thank you. I have this terrible awkwardness. I feel like I would have if I had learned Spanish the first year and over the summer forgotten all of it. And then gone to Spanish II, knowing I didn't even know Spanish I. I came to this hearing expecting that it would be a little simpler for me. Dr. Jensen, you start out by basically saying, in my terms, we can't really diagnose. We've got to have a good diagnosis of it, so we have to make sure the experts do it.

And, I guess, I should infer that there is really no scientific test, but people better attuned to it have an idea, be it very subjective, when someone should have Ritalin or have this drug. And when they have ADHD and so on.

So, first off, am I off base in my beginning comments?

Dr. JENSEN. Yes, sir; you're off base. Perhaps I should have been more clear. What we mean is that there is a characteristic pattern of signs and symptoms that begin before a child is age 7 that are

reported historically from multiple informants. Now, that may sound just a little bit loosy-goosy at first.

Mr. SHAYS. You're fine so far.

Dr. JENSEN. So, in addition to occurring in home settings, it must occur in school settings.

Mr. SHAYS. Right.

Dr. JENSEN. That same pattern of characteristic signs and symptoms that co-occur—they have to form a pattern. It isn't just a little bit of fidgetiness one day and a little bit of hyperactivity the next day and a little bit of impulsivity the third day. It requires that these symptoms cluster together, so they form a characteristic profile and they result in impairment in the child's home, educational, and peer relationship settings.

Now, what can we say about that? Is this just something that anyone could do? Well, no, sir. And the reason not is because, in addition to establishing the presence of those signs and symptoms, it has to be discriminated from depression, learning disabilities, competing medical causes such as hormonal abnormalities, problems with vision or hearing, or learning disabilities, for example. So a complete evaluation is necessary.

So what that all suggests is it takes a medical expert, just as any diagnosis would require. Now, is medical expertise always being applied? That's the difficulty, most of all. It isn't so much——

Mr. SHAYS. The question is: Is the expertise always being applied?

Dr. JENSEN. Is medical expertise and a complete assessment always being applied? And there's the rub. It's not. In many instances, we'll find that an evaluation may take place in 30 minutes. That's inadequate. We may find that information in terms of the child's school behaviors is not being obtained. That's inadequate. In those instances where one is flying, if you will, somewhat more by the clinical seat of one's pants, those problems are not reliable nor may the children have a valid diagnosis. So what's missing is the comprehensive evaluation.

When that comprehensive evaluation is done in the way I've outlined, then you'll find that one medical expert will agree with another medical expert—as with any of our conditions, whether it be a pneumonia, cancer, whatever, medical experts who are well trained in the condition can make reliable diagnosis and can agree. But it takes this combination of information, historical interviewing, and ruling out the presence of other competing signs and symptoms.

A good analogy is hypertension. To the extent that one takes a blood pressure, one may find that the blood pressure is elevated on a given day but it's not the next. So, often, the physician requires that the person have multiple assessments across multiple settings, for the really comfortable saying that this is the diagnosis of hypertension, all simply established by a blood pressure cuff, if you will, a sphygmomanometer on the arm. But only then do the series of tests proceed to see if a cause of that particular pattern of hypertension can be found. In many instances, it can't, and we call it idiopathic. That means we don't know exactly what the cause is. Other times, we find a tumor.

So it's very much the case of ADHD. Do we find a characteristic pattern? Is it stable over time, over situations? And it results in impairment in a child, just as hypertension leads to early stroke or heart disease. So we know that these difficulties lead to later difficulties, as well as current difficulties.

The pattern of the definitive test, though, of the cause or the type of hyperactivity or attention deficit remains elusive, just as it does for most instances of high blood pressure, that we find in that particular combination of genes. So I didn't mean to be impolite, sir, but I was trying to make a strong point.

Mr. SHAYS. We don't use the 5-minute rule for obvious reasons here. Dr. Danielson, do you have any point you want to make before I pursue some questions? And I also want to say to Dr. Schiller, you're more than welcome to jump in here. So, with the power invested in me, I give you that authority.

Do either of you have any comment you want to make before I go on?

Mr. DANIELSON. No; not to that.

Mr. SHAYS. Just to press my point a little bit, though, there is no diagnostic test; is that correct?

Mr. DANIELSON. Diagnostic tests, I'm not——

Mr. SHAYS. Something that gives you a readout that says you have this problem.

Mr. DANIELSON. So you would be talking like a brain scan or something like that.

Mr. SHAYS. Yes.

Mr. DANIELSON. OK. I'm certainly not the expert on that, but not to my knowledge.

Mr. SHAYS. Dr. Jensen.

Dr. JENSEN. That's correct, sir. There is no single diagnostic test. What we do have are diagnostic criteria that will reliably establish the presence of the condition. That's what I meant by the characteristic signs and symptoms.

Mr. SHAYS. Say that last response again.

Dr. JENSEN. While there is not a diagnostic test, there are diagnostic criteria that can then be reliably applied to make the definitive diagnosis with the child. So what that really——

Mr. SHAYS. Are you comfortable using the word, "definitive"?

Dr. JENSEN. Excuse me, sir?

Mr. SHAYS. Are you comfortable using the word, "definitive"?

Dr. JENSEN. Yes; in expert hands, absolutely. That is the issue. I think it's expert diagnosis.

Mr. SHAYS. I was going to ask you the questions of whether the prospects of developing a diagnostic test and finding biological markers to accurately diagnose the disorders. But you're implying that we've been there, that we're there.

Dr. JENSEN. No, sir; I'm saying that we haven't found one, yet. But, for example, just in the last 3 to 5——

Mr. SHAYS. What haven't found? That's what I'm trying to find out.

Dr. JENSEN. Well, just in the last 3 to 5 years, new tools have come online. For example, new positron emission tomography scanning images that become available; or the magnetic resonance imaging [MRI] scans: very much more sophisticated than things that

were available just 5 and 6 years ago. And it's been these tools, these new tools, some of them appropriate for children, that have allowed us to demonstrate the differences in certain areas of the brain, certain nuclei, brain structures that are different, smaller in size in some instances, than children without ADHD.

For example, another form of electroencephalograms, new forms of these are becoming available that allow us to demonstrate lower areas of activation of the brain, that the brains are actually underperforming or underactivated on some of these ADHD children. So you can differentiate ADHD children from other children.

How do those—how good would those be as a single test for the clinician to use in his office? Not good yet—yet. But down the road, we think these kinds of tools will make it more possible.

Now, in actual fact, sometimes these tools are applied in clinical settings, but because they don't reliably discriminate every ADHD child, they really result, if you will, in a number of false positives, as well as a number of false negatives. Just like, if you could imagine, the risk of telling somebody they have a positive test for AIDS, when the chance of having a false positive is 30 or 40 percent.

Well, that would be a terrible thing to say to somebody to have a positive test for this diagnosis when the tests may be wrong. And that's the level the tests are at now. They're moving. They're improving. But they shouldn't be used at clinical settings without better research to be able to definitively say, along with a clinical diagnosis, this is a reliable marker. That's where we're headed.

Mr. SHAYS. So that says to me, this is a very subjective process still. And what I'm hearing you say—and I don't mean to try to—I want you to know how you come across to me and then I want you to correct me if I'm wrong. What that says to me is that it is still very subjective.

And your response to me, as I hear it is, with an expert, it's not—there is still a science to it. I'm just trying to understand the science of it.

Do you want to correct me?

Dr. JENSEN. No, I think, sir, what I would say is that if you put two experts in a room and you have them take a child with ADHD and don't tell them what each is doing, but make sure they're well trained and they have the same kind of information and have them interview that child and that family and that core of information that is obtainable through some of the medical tests to rule out competing causes, et cetera, you'll find those experts will agree 85 to 90 percent of the time that this is a bona fide case of attention deficit disorder.

Now, if you give experts information in the same way, say, from an x ray on establishing the presence of tuberculosis, if you will, experts will only agree maybe 50 to 60 percent of the time; hypertension, 50 to 60 percent of the time; because of the unreliability of measurement.

Now, in the case of tuberculosis, we can go in and do a biopsy. In the case of hypertension, we can followup to find some other causes. In this case, we can't biopsy the brain.

Mr. SHAYS. What is the negative of misdiagnosing and prescribing Ritalin, for instance? What would be the negative if that child was misdiagnosed? Is there any negative?

Dr. JENSEN. Well, the negative would be that the child would then receive treatments that weren't tailored for his or her given needs.

Mr. SHAYS. And what would be the effect?

Dr. JENSEN. Well, if it were methylphenidate, or Ritalin, it might be some of the same effects of Ritalin, if you will, methylphenidate, on children without ADHD are the same as children with ADHD. So you may find increased concentration, decreased fidgetiness. Let's say this is not a true case of ADHD. So some of the negative effects are, if you will, the medical diagnosis and there would be other problems that should be responded, but also some of the positive effects of methylphenidate might also be the same.

Mr. SHAYS. I'm trying to understand; is there a concern that if ADHD is misdiagnosed, it doesn't really matter because there is still a benefit and there won't be a real negative. So, when in doubt, apply the drug rather than not apply it? That's the question I'm asking.

Dr. JENSEN. It's a very important question, because we have been concerned. And some of the studies that have been done suggested that, sometimes the practitioner thought that they could use the medication to make the diagnosis. And that's incorrect. And so in some recent surveys that were done, exactly that test was being applied as if it were definitive, which it's not. And so that would be inappropriate. And, actually, NIMH scientists established the fact that you can't use it as a diagnostic tool, because normal children also have increased attention and decreased activity under those kinds of conditions.

So, the other negative, I would say, would be that the child's problems, whatever they might be—whether it perhaps be anxiety or depression or other circumstances, medical difficulties, et cetera—would not be recognized and would be treated as if the problem were attention deficit disorder, which it would not be.

Mr. SHAYS. I don't quite understand the ethics of how you determine the viability of treatment with a child. I mean, you can have an adult and you can basically level with them and say, you know, we're going to have this group and we're going to have this group and we're going to—let me just tell you where I'm headed here.

You diagnose the challenge, but you haven't decided what the approach is to resolving their challenge. One might be with drugs. One might be just trying to deal with it in a behavioral way without drugs.

But how do you come to a conclusion when you're dealing with children? Are we allowed to ethically take a group of young people, who we all think have the same problem and treat them differently? Not tell them. Give them drugs in some instances and not in others? Can you give me a little insight?

Dr. JENSEN. So you're referring to like what we do in a clinical setting when we treat a given child?

Mr. SHAYS. Yes; but a clinical setting with a child, not an adult.

Dr. JENSEN. Yes.

Mr. SHAYS. Is there any ethical element that's different with a child than it is for an adult?

Dr. JENSEN. Yes, sir; absolutely. First of all, when you approach the treatment of the child, in addition to making sure that the par-

ent has full and informed consent about the risks and the benefits for the child, it's always right to get assent from the child. And by assent, what we mean, the child to the extent that he or she is capable, given their age, understands the treatments, has—is engaged in wanting to comply with the treatment, understands their benefits, as well as the potential side effects.

So, for example, when I treat a given child, I always make him or her a full partner and say, "Look, Johnny, here is what the situation is."

Mr. SHAYS. What is the age usually of a child; 8 years old; 7?

Dr. JENSEN. Eight, seven would be very typical. Now, with younger children, their difficulty to understand treatments may be less. So just as the pediatrician may say, look, you have strep throat and I'm going to give you an antibiotic, the child probably may not comprehend. And sometimes the parent has to act, as a good parent does, and make an informed judgment. But it's always in the area of these behavioral kinds of conditions that it's very important to wrap the child into making him or her a full partner in the treatment. And that means getting her assent and compliance.

Mr. SHAYS. I'm curious as to how the school system—I mean, I see the parent as being very key with the child. I see the medical community being involved, either by the parent or the school system. I guess what I want to know is, how does the school system come into play here?

Dr. JENSEN. Many of these children, of course, with their school age, are going to—their behavior may be first noticed in the school setting. Often, the parent may be aware if the child isn't diagnosed before entering school. The parent may be aware that the child's development may be somewhat atypical, the behavior may be somewhat atypical. But for many children, when you get them into the structure of a school situation, it's when the children really stand out as being developmentally somewhere else other than where a majority of the children are.

Does that respond to your question?

Mr. SHAYS. It does somewhat. I'm still wrestling with it. Let me just say historically, has the real promoter been the school system or has it been the parent in past years, maybe it's evolved to be more the parent now? Now, originally, did we see a lot of emphasis coming—a lot of encouragement coming from the school system to have a child diagnosed and to get treatment?

Dr. DANIELSON. I think in the case of ADD, probably not the school. And, in fact, to some degree, that's what our information campaign was about, was getting information to teachers and administrators and other school people because there was a lack of—a general lack of information. So I think for the most part, it probably—I don't know this for a fact, but I would have to speculate that it probably was not coming from the schools.

Mr. SHAYS. I should have clarified this sooner. But when I say ADD or ADHD, I'm using them interchangeably.

Dr. DANIELSON. That's OK, sure.

Dr. SCHILLER. Excuse me, Mr. Chairman.

Mr. SHAYS. Yes.

Dr. SCHILLER. I'd like to introduce——

Mr. SHAYS. I've been waiting for you to jump in. Why don't you move the mic down.

Dr. SCHILLER. I'd like to introduce the information products that the Department produced in collaboration with its 12 partners. And as we'll mention, these information products were based on a research synthesis and were designed to meet the needs of families and educators. And, I think, in response in the beginning, in response to your question, if families came to Congress and said that they needed some help in seeing that their children were served in the public schools. And how could Congress and the Department of Education help children with ADD receive appropriate services?

Mr. SHAYS. It's interesting, though, you say the parents, because—and nothing scientific about this, but I probably have more teachers coming to me and saying, too many of our kids are being drugged in the school system. That is something that doesn't happen often, but the comments are made by the teachers. We didn't used to have this situation where this child has this prescription, and another child has another prescription. I didn't used to hear that.

I make an assumption that it isn't coming from the individual teachers. And I'm just wondering, is it coming from specialists within the school systems? I mean, I'm just trying to sort this out for myself. This is the first hearing. Ultimately, this won't be like Spanish II when I have forgotten the Spanish I course.

But I am just trying to get a base in which to work.

Dr. SCHILLER. Well, actually, that might speak to the success of the information dissemination campaign. When we began this campaign in 1990, very little was known about educating children with ADD in the public schools. And, over time, we have clarified our Federal policy; that is, the legislation that can help serve these children. We have synthesized the research. We communicated it broadly through our 12 dissemination partners and through the media.

And so, possibly, over the last 6 years, through this dissemination effort, there is more awareness. And I'd like to say better understanding, but I'll say more awareness about children who exhibit these characteristics. And teachers are asking, What can we do?

Mr. SHAYS. This is not meant in any real negative way. It's just something I'm trying to sort out. It's an uncomfortable feeling thinking that the Federal Government has, quote, unquote a policy. I begin to think of it in terms of one-size-fits-all approach. I need you to define what you mean by policy, because it seems to me the jury is still out.

For the Federal Government to really step in with any definitive policy, what do you mean by policy?

Mr. DANIELSON. Maybe I can respond to that. The policy issue that we clarified is that there was confusion over the degree to which children with attention deficit disorder were eligible under the Individuals with Disability Education Act. That is, was it—it was not a named disability category, because in the legislation, there were, I think, at the time 11 disability categories actually named in the legislation. Mental retardation, learning disabilities,

deafness, blindness, orthopedic impairments, and so forth, that were named in the legislation.

And since ADD wasn't actually named as a disability category, I think parents were finding that when they would go to the school system and say that I need some accommodations for my child in the classroom, which might be something as simple as, would you seat my child in the front of the room close to you, because they are often inattentive and they don't hear the assignment. So they're not getting their homework done and so forth.

And that sometimes as simple as that, a parent might find that a school district was unwilling to provide even that simple accommodation.

So parents were saying, well, do these policies of IDEA, these provisions that deal with children with disabilities, do they not also apply to children with attention deficit disorder? So what the policy clarification did is it set out under what circumstances a child with attention deficit disorder would be regarded as disabled under the IDEA, and, therefore, the provisions of IDEA then would apply to that child, which include a set of——

Mr. SHAYS. Yes; I understand that part. Thank you. I understand what you mean about policy. I have two other questions I want to ask and then we'll get to our next panel.

I'm wrestling with the fact that—and maybe it's my puritanical background here, my puritan background coming from New England. But I want a sense of accountability that the child does not have one more excuse to justify why they couldn't do something, and a parent not have that excuse. What happens when a parent absolutely insists that it's not their fault, not their child's fault, in terms of behavior that could be dealt with without a drug and they absolutely insist that they need, say, methylphenidate. I'm assuming that's the basic drug. I mean, that's the generic drug type.

But what happens under those circumstances?

Mr. DANIELSON. Who are you addressing that question to?

Mr. SHAYS. Either one.

Dr. JENSEN. Sir, do you mean if the parent really insists that this is the treatment of choice, or the school insists?

Mr. SHAYS. I mean, this happens time and again in our public school systems. When a parent says my child is not getting the attention they need, you're ignoring my child, this is not a problem that I have in terms of discipline with my child. Or the parent says it is a chemical problem, my child needs this drug and the parent insists on it. What happens then?

Dr. JENSEN. Perhaps I might respond first. The critical thing has to do with the accurate diagnosis. And, if the diagnosis is not accurate, treatment may not be appropriate. And so, if a parent comes to me and says to me as a clinician, that this child needs methylphenidate, my first question is, let's do—my first step is to do an appropriate evaluation to determine the presence or absence of the diagnosis. And if indeed ADHD is there, I won't withhold the treatment if I have a suffering child. I would think it would be wrong to do so. But I'll put that treatment in place in concert with the behavioral interventions and working with the school system, rather than as a magic bullet.

Mr. SHAYS. This is the last question and then we'll get on to the next panel. What I am then trying to sort out is how we treat a mental health problem differently than we treat a physical problem in terms of how insurance reimburses and so on. It strikes me that there is a tremendous incentive to make this a physical chemical problem rather than a mental one.

Dr. JENSEN. Perhaps I could respond, sir. ADHD really is a disease of the most complex organ system of the brain. And while the exact markers and tests for its definitive characteristics, a one-shot test, aren't yet available—and we don't have that for most of our conditions, apart from autopsy or histology slides.

Mr. SHAYS. But, is it true that the payment schedule for insurance different based on how it's diagnosed?

Dr. JENSEN. Yes, sir. It's very typical that the mental disorders, as you know, are reimbursed differently than—but whether one calls this a brain disorder or a behavioral disorder is still in the general rubric of the diagnostic, the DSM–4. And insurance companies, regardless of etiology, are precluding—some insurance companies would preclude their coverage.

Mr. SHAYS. The challenge—and I just want to pursue this a little bit more. If you make a diagnosis where you will not use Ritalin, for instance, is a brand, but use another drug, then are you reimbursed differently?

Dr. JENSEN. No, sir; I don't believe that would be the case.

Mr. SHAYS. What happens if it's a behavioral challenge without the need of drug? Isn't there a point where the financial resources simply dry up?

Dr. JENSEN. It would depend on the coverage for a given child or family. And I guess all companies would vary to the nature of that.

Mr. SHAYS. But we're wrestling with this right now in Congress. We're deciding whether mental health will be treated on a par with physical health. If it's not, I'm just trying to get a handle on the fact that there's a certain point where there will not be the financial resources to deal with a very real mental health problem.

Dr. JENSEN. That's right.

Mr. SHAYS. And this is not an issue. I'm just making this up. This is not a factor in the whole process?

Dr. JENSEN. To the extent that one moves to one treatment versus another treatment? It has to be a factor. Access to care and provisions of the care certainly affect what families can pay for and what the clinicians are likely to make available based on what's offered under the family's plan. That's absolutely right.

Mr. SHAYS. Any other comments before we go to our next panel? We, believe it or not, may get you back here, because you've all been very helpful in helping us sort this out. We're just touching this issue and we may have a number of other hearings before we come to any conclusion on it. I thank you all for coming.

Dr. JENSEN. Thank you.

Mr. SHAYS. I'm going to get some housekeeping out of the way, Mr. Barrett, while you're here. I ask unanimous consent that all members of the subcommittee be permitted to place any opening statement in the record and that the record remain open for 3 days for that purpose. Without objection, so ordered.

I would also ask unanimous consent that our witnesses be permitted to include their written statements in the record. And, without objection, so ordered.

At this time, we will call our next panel, which is Mary Richard, Howard Morris, and Maureen Gill. And I'll ask them to testify in that order. And if they would remain standing, I'll swear them in.

[Witnesses sworn.]

Mr. SHAYS. Note for the record that all have responded in the affirmative.

We're happy to have you summarize your testimony. We're also happy, if you choose to, to submit your written testimony, but then maybe respond to the dialog that's already taken place if you feel so inclined. So you've got lots of options here. Mary Richard, we'll start with you.

STATEMENTS OF MARY RICHARD, NATIONAL PRESIDENT OF CHILDREN AND ADULTS WITH ATTENTION DEFICIT DISORDER [CH.A.D.D.]; HOWARD MORRIS, THE ATTENTION DEFICIT DISORDER ASSOCIATION [ADDA]; AND MAUREEN GILL, MOTHER OF TWO SONS WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER [ADHD]

Ms. RICHARD. Mr. Chairman and members of the subcommittee, I thank you for the opportunity to appear before you today. I am speaking to you both as a national president of CH.A.D.D., otherwise known as Children and Adults with Attention Deficit Disorder, and also as the mother of two teenage sons, John and Michael, who, over 10 years ago, were diagnosed with attention deficit disorders.

I've submitted a statement that I now request be made a part of the record.

CH.A.D.D. is a national nonprofit organization with over 35,000 members and 600 chapters in the 50 States. It was formed by parents in 1987 for the purposes of providing family support, advocacy, professional and public education, and also encouraging and disseminating results of scientific research about ADHD.

These things are carried out by CH.A.D.D. in a variety of ways. Since its establishment, CH.A.D.D. has provided a support network for families and for parents of children with ADD and for adults with ADD. We have also published the CH.A.D.D. educators manual, which is a handbook for teachers and other school professionals. Today, CH.A.D.D. publishes the CH.A.D.D.ER Box, a bimonthly newsletter, as well as Attention, the quarterly news magazine. Both of these contain excellent information about research, practice, and policy issues that affect individuals with ADHD.

On the Federal level, we advocate for people with ADHD through our Washington, DC, office; and on the State level, through our ADD State councils. And this fall, we will hold again for the eighth time our annual international conference on attention deficit disorders in downtown Chicago.

CH.A.D.D. parents have long thought to ensure that their children receive a good education. As you heard, in September 1991, in fact, at our conference that fall, the Department of Education issued the policy clarification memorandum that clearly stated that children with ADD are eligible for special education services and

related services when their ADD adversely affects school performance.

Despite this memorandum, however, there still continues to be a great deal of confusion. In fact, on a daily basis, CH.A.D.D. receives calls from parents who are being told that their schools do not provide assistance for students with ADD, or do not know how to help them.

CH.A.D.D. is working to address this by encouraging the Department of Education and a part of their IDEA reauthorization process to amend its regulations to include ADD on the list of impairments that may qualify under the other health impaired category.

As we press the future, CH.A.D.D. believes the Department of Education must ensure that no student, whether an elementary or secondary school, with ADD, go unrecognized and unserved and left to fail. It also remains critical that schools be even further informed of their responsibility to provide special education and related services for students with ADD who need this help.

The Department of Education has in recent years played a real leadership role in disseminating information about the disability as well as about the best practices that are known in the areas of parenting and educating these students. And CH.A.D.D. stands ready to work with them, to continue our partnership, to disseminate this information, to also work with our children's teachers and schools to accomplish these objectives.

CH.A.D.D. members and the public have also benefited another venue from the Federal support of the groundbreaking research that was heard about today on ADD, undertaken by the National Institute of Mental Health, from the landmark brain imaging studies of Dr. Alan Zametkin in 1990 to Judith Rapoport's recent important studies identifying a series of brain-based anomalies in individuals with ADHD, the National Institute of Mental Health has contributed significantly to the scientific understanding of the basic brain mechanisms of this disorder.

We've heard a lot from Dr. Jensen about the important work on the multisite collaborative study of medical and nonmedical treatments for individuals with ADHD.

And CH.A.D.D. believes that it is essential that Congress support funding for research in order to learn more about both, because of the disorder and the best treatments for ADD.

We also encourage National Institute of Mental Health professionals to work for the development of comprehensive diagnostic and tools and protocols for use by professionals for making accurate diagnosis. I would thank the committee for today's hearing and the opportunity to tell you about CH.A.D.D.. I'm looking forward to continuing to work on behalf of children like my sons, John and Michael, that they may get the help they need to support their efforts to be successful in school and in life.

[The prepared statement of Ms. Richard follows:]

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to appear before you this afternoon. I speak to you today both as the National President of Children and Adults with Attention Deficit Disorders (CH.A.D.D.) and as the mother of John and Michael, my two sons, who both have attention deficit disorder (ADD).

CH.A.D.D. is a national nonprofit parent-based organization with over 600 local chapters and 35,000 members working for the success of individuals with ADD. Based in Plantation, Florida, CH.A.D.D. was formed in 1987 and through family support and advocacy, public and professional education and encouragement of scientific research, CH.A.D.D. helps those with ADD to reach their inherent potential.

Since its establishment, CH.A.D.D. has provided a support network for parents of children with ADD and adults with ADD, and served as a source of the latest scientifically-based information about ADD. CH.A.D.D. has published the *CH.A.D.D. Educators Manual*, a handbook for teachers that examines ADD in the classroom and offers strategies for how to effectively teach children with ADD. We publish a bimonthly newsletter, *The CHADDER Box* and a quarterly magazine, *ATTENTION!®*, which informs members and the public about the latest information available on research, practice and policy issues which impact individuals with ADD. CH.A.D.D. holds an annual conference that brings together national and international experts on ADD to present research findings and share information. CH.A.D.D. also advocates for individuals with ADD on the federal level through our Washington office, and on the state level through our state councils.

One of CH.A.D.D.'s primary objectives has been to ensure that ADD is recognized and appropriately managed within educational settings, so as to provide the best educational experiences to children with ADD. Historically, many children with ADD lacked access to the legal protections available to children with disabilities in the Individuals with Disabilities Education Act (IDEA), because schools either did not know that ADD was a disability covered under IDEA or they did not have a clear idea about how to serve students whose educational performance was adversely impacted by ADD. Parents and teachers who sought educational services for students with ADD were often told that students could only qualify if they met the eligibility criteria for other disabilities, such as learning disabilities or serious emotional disturbance. Thus, when children with ADD did receive services, it was often without regard to their primary disability, ADD.

In the late 1980's, Congress became aware of the difficulties many children with ADD were experiencing in our public schools. In 1990, Congress directed the U.S. Department of Education to conduct a "Notice of Inquiry" to solicit comments about how public schools throughout the nation were serving children with ADD. The Department received thousands of letters from parents who told of the difficulties, frustration and failure that their children with ADD were experiencing in school due to a lack of appropriate educational programs and an understanding and awareness of ADD. In addition, educators wrote about the absence of any information to help them meet the challenges of

educating students with ADD. After careful review of the comments, the Department issued a Policy Clarification Memorandum in September of 1991 which stated that children with ADD were already eligible for special education and related services under the Other Health Impaired category of Part B of IDEA when their ADD represents a "chronic or acute health problem resulting in limited alertness which adversely affects educational performance." The Memorandum went further to state that schools have the additional responsibility of determining if Section 504 of the Rehabilitation Act of 1973 applies to the child, should the child not qualify for services under IDEA.

Despite the 1991 Policy Clarification Memorandum and subsequent efforts of the Department to educate parents and educators, much confusion still exists today in public schools across the nation about where and how to serve students with ADD. On a daily basis, CH.A.D.D. receives calls from parents who are unable to obtain proper educational services for their children with ADD. They relate heartbreaking stories of frustration and academic failure. They tell us their school does not have anything to offer students with ADD because they don't qualify for any services. CH.A.D.D. is actively working to eliminate this confusion by encouraging the Department of Education, as part of the IDEA Reauthorization process, to amend its regulations to include ADD within the list of impairments which may qualify under the Other Health Impaired category.

As we approach the future, we believe that the Department of Education must ensure that no child with ADD who needs special education and related services goes unrecognized, unserved and left to fail. It remains critical that school systems be informed of their responsibility to provide special education and related services for children with ADD. The Department of Education in recent years has played a leading role in disseminating information about the disability as well as effective educational practices regarding ADD to parents and educators. CH.A.D.D. looks forward to working with the Department in the future to accomplish these objectives.

CH.A.D.D. members and the public have benefited significantly from the ground breaking research on ADD that has been undertaken by the National Institute of Mental Health (NIMH). From the landmark brain imaging studies of Dr. Alan Zametkin in 1990 to Dr. Judith Rapoport's important studies identifying a series of brain-based anomalies in individuals with ADD, the NIMH has contributed significantly to the scientific understanding of ADD. Dr. Peter Jensen is currently at work on multisite collaborative studies of medical and nonmedical treatments for individuals with ADD.

It is essential for Congress to increase funding for research in order to learn more about the causes of and best treatments for ADD. We encourage NIMH professionals to become active in assisting with the development of comprehensive diagnostic and assessment tools which would assist professionals in properly diagnosing cases of ADD. Additionally, we look forward to learning about the ongoing studies at NIMH which will afford a greater understanding of the neurobiological basis of ADD.

The multitude of information available about ADD was not available for parents when I had my first introduction to ADD, as the mother of John, who from his first day, displayed the early signs of what was later diagnosed as ADD. John was a sleepless baby who cried inconsolably day and night. Our pediatrician pronounced him a healthy, albeit fussy baby, but as John's mother, I knew it was more than "fussy."

Two years later, John's brother Michael arrived, and gave a repeat performance, complete with wakefulness and wailing. Those who think all children are hyperactive have not lived with children like John and Michael. They guaranteed at least an 18-hour day of non-stop activity. In spite of our fenced-in yard and child-proof house, it was difficult to take an eye off them for even a moment without risking potential mishap. My husband and I were concerned not only about their safety, but about their development. Although both boys seemed to be very bright, their short attention spans did not permit them to enjoy relaxed activities or to develop some of the skills that require sustained efforts, such as listening to bedtime stories.

When it came time for preschool, the boys attended a Montessori school. The teachers there helped us address some of our concerns, and gave their all to establish a safe and happy preschool environment for the boys. In spite of this, by the time our sons were three and five years of age, we were exhausted and left with many unanswered questions.

In spite of our sons' otherwise good health, our pediatrician remained in close touch with us, as he was concerned about the whirlwind behavior that was constant for John and Michael. We attended the same church, and he and his wife sat behind us each week, so he had ample time to observe their behavior. Eventually, he recommended a thorough assessment. After comprehensive testing and evaluation, both John and Michael were diagnosed with ADD.

Recognizing that the boys had ADD was a life-changing event for our family. Finally, we were able to understand the problems John and Michael had. The boys began individualized comprehensive treatment plans for their ADD which included educational accommodations, counseling and medication. Both have benefited enormously from treatment. Receiving the proper diagnosis and treatment has empowered them to gain a hold on their lives, exercise responsibility, and achieve success in school, at home and with their peers.

Currently, John is 16 and Michael is 14. John receives services through an educational program based on Section 504. Michael receives educational interventions for his ADD-related needs in the resource room at his junior high school. They work with a tutor that my husband and I provide for them two nights a week. Both of my sons are honor roll students. They are Boy Scouts, are active in their church youth groups and have extra-curricular interests at school. Raising John and Michael has been challenging, however not a day goes by that we are not thankful for the knowledge that has equipped us with an understanding of what they need to grow and achieve their potential.

In closing, I would like to commend the Human Resources and Intergovernmental Relations Subcommittee for today's hearing focusing on ADD. I thank you for the opportunity to share information about CH.A.D.D. and about my sons with you. CH.A.D.D. believes that Congress and the Federal Government have the capacity to continue to make a difference in the lives of individuals who have ADD and those who care for them. I look forward to continued work between CH.A.D.D. with the Department of Education in order to ensure that children like John and Michael receive the educational services they need in order to succeed. And by ensuring continued support of the research activities at the National Institute of Mental Health, we can add to our understanding of Attention Deficit Disorder.

I would be happy to answer any questions.

Mr. SHAYS. Thank you very much, Ms. Richard. Mr. Morris.

Mr. MORRIS. I'm Howard Morris. I'm vice president of marketing of the National Attention Deficit Disorder Association. On behalf of myself and the board, I'd like to thank you for this opportunity to testify before this committee on this very important issue of attention deficit disorder.

ADDA is a national organization dedicated to advocating for the needs of children and adults with ADD. In particular, ADDA is focused on the issues associated with adults and young adults with ADD. While we believe ADD has been a feature of human existence from the beginning, it has without question become an issue inseparably associated with the 1990's. Yet, when one looks at the vast majority of what's reported in the media about ADD, it's easy to conclude it's only about two things, about children and the stimulant medication, Ritalin.

What I hope to accomplish in my testimony here, this afternoon, and in our discussion is give you a larger sense of ADD, one that perhaps starts to break this mold. Attention deficit disorder is far more than a childhood condition. ADD is something that most people with it, have across a life span. And the treatment for ADD is far more than just a magic pill.

ADDA also has serious concerns about misdiagnosis that you've been discussing today. And the potential for people on medication who simply should not be, and vice versa. These are issues that we've addressed at length in our written statement and we think are important to explore.

I come to this discussion as my other panelists do here with personal experience with ADD. I was diagnosed for years at age 38 before ADD became a media star and before most people even heard the term. I certainly had never heard it before.

At age 38, I had spent my whole life thinking something was terribly wrong. But I couldn't put my finger on it. My life was a series of half-finished projects, relationships that would fizzle out of neglect, money problems, missed opportunities, angry outbursts, and a general feeling that life was just completely out of control, that things just spun.

I had this for my entire life. Despite a creative talent that led me to perform, I couldn't sit back and read a book without my eyes glazing over. By the time I get to the bottom of the page, I had forgotten the character's name that was mentioned at the top of the page. I forget my wife's name at a party. The number the information operator gave me was gone by the time I hung up the phone.

Again, while time doesn't permit me to elaborate in full, my experience is just like millions of other adults with a neurobiological disorder known as attention deficit disorder. People who are driven to distraction, that skip from job to job, from one unfinished project to the next and find themselves with incomplete educations, broken families, and destroyed credit.

And while some may characterize ADD as simply a metaphor for the rush sound bite of society in which we live, where everyone seems to have a little ADD, the fact is that people who have this disorder experience life in a different way than people who don't. Everyone loses their keys occasionally. The ADD person loses them several times a day, every day. They lose wedding rings, important

documents, and countless other things. They lose ordinary words when they're engaged in everyday conversation. They procrastinate as a way of life. There never is enough time for anything.

Everyone gets drowsy and lets their mind wander while reading a book, the person with undiagnosed and untreated ADD may never get through a substantial book their whole life. Happily, most people properly diagnosed with ADD and appropriately treated come to know a happier, more successful and dramatically productive life. They discover that ADD also comes with a large number of very positive traits and enhance sense of creativity, drive, humor, empathy, intuition, which they're not able to access as undiagnosed people with ADD.

Add to this concern is the perception that ADD is overdiagnosed and that medication is overprescribed. We feel that ADD is paradoxically both overdiagnosed and underdiagnosed. It's a complex problem. We feel that the media explosion about ADD has led to a glut of people approaching their primary care physicians, wondering if this could be the problem for them or their children. We find that many physicians, anecdotally, that many physicians neglect to fully evaluate their patients for the full range of what may be going on.

In fact, many physicians, as was discussed briefly, actually use Ritalin as a diagnostic tool. That is, if it works, you have it. If it doesn't, you don't. This is completely inappropriate and results not only in false positive diagnosis, but false negatives. It robs patients of accurate diagnosis that can ameliorate whatever difficulty is really going on.

Therefore, ADDA is creating guidelines for physicians, primarily primary care physicians that can help them down the road toward accurate evaluation of patients who approach them with potential problems. Like our colleagues at CH.A.D.D., ADDA urges Congress to support the full range of ADD research, educational efforts, and appropriate accommodations for people that genuinely have attention deficit disorder.

I thank you very much for the opportunity to be here and look forward to answering your questions.

[The prepared statement of Mr. Morris follows:]

INTRODUCTION

The National Attention Deficit Disorder Association (ADDA) greatly appreciates the opportunity to testify before the Subcommittee on Human Resources and Intergovernmental Relations on the important issue of Attention Deficit Disorder. ADDA is a national organization, dedicated to advocating for the needs of children and adults with Attention Deficit Disorder (ADD) and their families. In particular, ADDA is focused on issues associated with adults and young adults with ADD. We seek to advocate by providing education, setting standards and guidelines for quality and accurate diagnosis and treatment, and serving as a referral and networking resource for individuals and groups concerned about ADD.

These goals are reflected in our Mission Statement:

- To increase awareness and understanding of Attention Deficit Disorders including what ADD is, how it impacts throughout life, and how to identify and properly manage it.

- To establish and advocate for appropriate standards of care for ADD that respect the uniqueness of each individual, and to facilitate the removal of all barriers to properly care for individuals with ADD.

- To increase the number of professionals who are trained to recognize and/or work with people impacted by ADD.

While we believe ADD has always been a feature of human existence, it has without question become an issue inseparably associated with the 90's. It seems like never a day goes by when ADD isn't being discussed, debated or maligned in the press, on a talk show, on the Internet, or on some form of broadcast media. Yet when one looks at the vast majority of these reports, it's easy to conclude that ADD is only about children and only about the medication Ritalin (Methyphenadate). We cannot stress strongly enough that this simply is not the case. A wide breadth of research has shown ADD to be a lifespan disorder and effects the individual differently at different ages.

Yet ADD is often associated with one particular mental image. It's the young child who squirms in his seat, who won't follow directions, who misbehaves, daydreams, blurts out impulsively and despite often being very bright, can't seem to live up to the performance of his peers. These are children that parents can't control, that teachers are constantly in conflict with, and that demand more of everyone's time and efforts to deal with. This is the child we associate with Attention Deficit Hyperactivity Disorder (ADHD).

What gets ignored in this picture, however, is the child without the hyperactive component; the child who daydreams, but doesn't cause trouble, the child who has extraordinary trouble concentrating on his or her homework, but sits quietly playing Nintendo for hours. The kids who leave in their wake scores of unfinished projects, who lose friends out of neglect, who never seem to be listening, and who bring home lousy report cards despite having extraordinary IQs.

While it's critically important to recognize that not all children who have these symptoms suffer from ADD, it's these children, and their hyperactive peers, that grow up to be adolescents, young adults, and fully grown adults who in large percentage live their whole lives with the neurobiological condition known as Attention Deficit Disorder.

As to the issue of medication, it's very important to recognize that this is only one component in the treatment of ADD, at whatever age. Equal emphasis on counseling, behavior modification, and a simple understanding of the disorder by the individual diagnosed are just as important. Typically, ADD is not effectively treated with just a pill. And Ritalin, while the most commonly prescribed and most thoroughly researched, is only one of many medications used to treat the disorder. Dexedrine, Cylert, and ADDerall are just a few of the medicines used to treat ADD.

ADDA believes it's extraordinarily important, especially at this juncture, for people in education, in government, in health care, in the insurance industry, in the media, and across the general public, to get the story of Attention Deficit Disorder right. To separate the myths and half-truths and outright misinformation from the facts. It's important because for millions of Americans, both children and adults, living with ADD is a daily reality. For those who've been diagnosed, grappling with the subtleties and challenges of treatment, medication, school, workplace and family issues is constantly at the forefront. Many cringe at the embarrassment of owning up to a disorder that some, who are uninformed about its realities, slough off and label as some kind of excuse or "disease of the week."

ADD is clearly neither of these labels. Symptoms associated with ADD have been a feature of mankind throughout history. Before we began to understand ADD from a medical perspective four decades ago, people with ADD were diagnosed by their peers, friends, family and employers purely from a moral perspective. The diagnosis was simply that they were bad people. That was their diagnosis. Unorganized and unfocused. Unable to follow through or complete what they say they'll do. Always in a rush to do what they've procrastinated until the last minute to do.

And while some may characterize ADD as simply a metaphor for the rushed, sound-bited society in which we live where everyone seems to have a little ADD, the fact is that people who have this disorder experience life in a different way than people who don't. Everyone loses their keys occasionally, the person with ADD loses them several times a day. Every day. They lose wedding rings, important documents, and countless other things. They lose ordinary words while engaged in everyday conversation. They

lose items that sit on the desk in front of them in plain view. They procrastinate as a way of life. Time is compressed and while 20 projects are always in the hopper, often nothing gets done. Everyone gets drowsy and lets their mind wander while reading a book, the person with undiagnosed and untreated ADD may never get through a substantial book his whole life. He or she is so distracted that by the time they've reached the bottom of the page, the character described at the top of the page is a complete stranger. ADD is something people who genuinely have it spend their lives struggling with. It's often amazingly painful. It's not a joke, and it shouldn't be an embarrassing label.

Nor should ADD be considered or used as an excuse. Undiagnosed, it's an explanation for many kinds of behavior. But with diagnosis comes a new framework, new understanding, and new responsibilities. The diagnosis of ADD can in many ways be compared to the discovery that a child needs glasses. Prior to diagnosis, a child with poor eyesight sees the world through fuzzy eyes. He doesn't know any different, because that's the way he's always seen things. His lack of response and understanding of what the teacher puts on the board is not an excuse, but a legitimate explanation. Yet when this same child grows older and learns to drive, the fact that he runs a red light and kills someone in an auto accident is not mitigated by the fact that he has poor eyesight. It's no excuse because it was his responsibility to wear his glasses. In the same way, diagnosis of ADD comes with the responsibility that one will seek appropriate treatment, and seek an understanding of how they can reduce or eliminate the negative effects of it in their life.

Happily, most people properly diagnosed with ADD and appropriately treated, come to know a happier, more successful and productive life. They discover that ADD also comes with a large number of very positive traits - an enhanced sense of creativity, drive, humor, empathy and intuition - which can be put to amazing use in their life.

At the same time, large numbers of Americans struggle with a life of undiagnosed ADD, or ADD that's been misdiagnosed as other maladies. These positive traits remain buried under an avalanche of symptoms that obscure their real talents and abilities. They travel through a daily existence replete with failure, frustration and fear. ADD is "full range" - that is, it goes from mild to severe, and cuts across all social and economic classifications. Those with ADD who have developed coping mechanisms, who grow up with positive role models and solid parenting, and who surround themselves with people that can attend to the mundane details in their life, often succeed at many of life's pursuits - even achieving great financial success. Yet even many of these people have a persistent ache that something is terribly wrong. Despite their success, life is a whirlwind that they can't quite get their arms around. There's never, ever enough time. People around them often find them untenable, irresponsible, rude, impulsive and forgetful.

Adults with undiagnosed ADD that don't grow up with the fortunate blend of support and learned coping mechanisms often lead lives full of financial failure, destroyed relationships, missed opportunities, angry outbursts, guilt, and a total feeling that life is completely out of control. They skip from job to job, from one unfinished project to the

next, and find themselves with incomplete educations, broken families, and destroyed credit. Throughout their life these people, again, are labeled as failures; as not living up to their potential, as quitters, and as completely disorganized. They walk around with destroyed self-images, and carry with them each day the gloomy feeling that something is terribly wrong with them - that they are either lazy, stupid or crazy.

For teachers, educators and school administrators, ADD is also a daily reality. In an age of overstuffed classrooms that challenge even the most talented teachers, they struggle with the difficulty of deciding who of the students that won't pay attention, that won't live up to their capabilities, that won't follow through on assignments, that simply won't settle down and behave - who out of these students is simply acting out of bad behavioral control, and who might have this thing called Attention Deficit Disorder. In the face of contradictory and often sensationalized stories in the media, they grapple with the spectacle of large numbers of students traipsing off to the principal's office to take their medication. In a time of ever tightening financial constraints, administrators and people in government wonder how best to allocate resources to maximize their impact and minimize their waste.

For health care providers, too, ADD is a complex issue that has demanded their attention. In the wake of widely varied media coverage over the past several years, doctors have been besieged by people who come to them wondering if this could be the reason for their child's or their own difficulties. They want to know about medications, therapy, research, and accommodations. They want a quick fix. In a world that moves quickly and where not a second goes by when another gigabyte of data is generated and yells for attention, keeping up with the right answers is a monumental task.

The ramifications of ADD on our society are profound. The costs associated with unemployment, criminal activity, and serious health ramifications including but not limited to auto accidents, drug and alcohol abuse, obesity, depression, and anxiety must be recognized. When we combine the health, social, educational, and economic impact of undiagnosed and untreated ADD, the cost for our society is staggering. ADD is a serious problem that must be aggressively and responsibly addressed now.

Whether you're a doctor, an adult, or a mother with a hyperactive child, Attention Deficit Disorder doesn't come with easy answers.

The landscape of ADD is full of stunning successes and failures. Medications and treatments that have literally changed people's lives. It's full of physicians, psychologists, researchers and a wide range of health care providers that are working miracles in people's lives every day. It's also full of misinformation, exaggerations, sensationalism, myths, scare tactics and people who simply want to use it to make a buck.

The explosion of Ritalin (Methyphenadate) prescriptions over the past several years for the treatment of Attention Deficit Disorder has raised serious questions about how this disorder is diagnosed and treated. Is it being appropriately diagnosed? Is stimulant medication the answer? Are people with other maladies being diagnosed with ADD

instead? To what extent do people who simply have behavioral problems get diagnosed with ADD and begin taking medication?

ADDA believes that Attention Deficit Disorder is simultaneously over-diagnosed and under- diagnosed. That is, many people are misdiagnosed with the disorder when their real problem may be something else, and at the same time, many people are either misdiagnosed and treated for other things when the central problem is actually ADD. Sadly, even more people, are never diagnosed with ADD at all, either because they never seek evaluation, their physicians discount the validity of the diagnosis, or, commonly, their medical insurance precludes appropriate diagnosis and treatment. These people either languish in the belief that their difficulty is simply one of character or will, or in the frustration that there is nothing they can do, even though they may indeed have ADD.

ADDA believes that many primary care physicians have not had the time or taken the opportunity to fully expose themselves to appropriate diagnostic protocols for ADD. Nor have a lot of these same physicians prepared their practice to appropriately treat ADD in a multi-modal fashion once its been diagnosed. Instead, these doctors often rely on medication to do the entire job of treating the ADD.

At the same time, the explosion of lay materials and the glut of media coverage has resulted in large numbers of patients that walk in the door having been "educated" through the media or through books, materials and support groups. Therefore, many patients that present with what appear to be "typical ADD" symptoms, are casually diagnosed without performing an appropriately vigorous differential diagnosis. In fact, the safety and efficacy of Ritalin often leads many to use the medication itself as a diagnostic tool. That is, if it works, then you have ADD, if it doesn't, you don't. As we'll discuss in the body of this statement, this simply is not an appropriate way to diagnose ADD, and leads to, again, false-positive and, just as often, false-negative diagnoses.

Therefore, ADDA advocates that all physicians and other health care providers who are going to diagnosis Attention Deficit Disorder become highly familiar with appropriate differential diagnostic methods for it, and become prepared to appropriately treat and manage these patients. Others should be made aware of when referral to other physicians and health care providers is appropriate.

We consider it our role to help in this process, through our professional education programs at our yearly national conference, and by making available to physicians materials, forms, and resource references they can use to become more informed.

The intention of this statement is to provide assistance for members of Congress to reach appropriate and balanced decisions in the legislative process with respect to issues that effect, either directly or collaterally, people who live with ADD. Millions of people in this country with ADD are counting on you to do the right thing. To protect their right to get appropriate treatment and accommodations, to assure that research is funded, and to fund projects which seek to educate all Americans about the realities of Attention Deficit Disorder.

We summarize our current state of understanding about ADD in this testimony, and its impact on contemporary society. We seek to propose an outline for a standard of medical care for ADD, and to define a set of objectives that our country should embrace in order to effectively and efficiently respond to the needs precipitated by the emergence of ADD as a critical issue in our society.

BACKGROUND INFORMATION ABOUT ADD

Attention Deficit Disorder (ADD) is a term used to describe a medical syndrome consisting of biologically-based chronic inattention. It's typically estimated to affect somewhere between 3 and 9% of the population. Individuals with ADD have inborn weaknesses in attention including low arousal, impulsivity, short attention span, distractibility, and poor self monitoring. These attention weaknesses are commonly associated with other symptoms or signs that indicate an immaturity or difference in nervous system development (e.g., gross/fine motor incoordination and the presence of soft neurological signs).

While the exact etiology of ADD remains unknown, the current medical literature strongly suggests that ADD is a genetic disorder that is linked to maldevelopment and/or malfunctioning of certain neuro-biochemical systems in those parts of the brain that are involved with controlling attention and arousal level. Several well controlled studies have suggested that there are differences in the brains of adults who were once labeled "hyperactive children" thus dispelling the myth that individuals outgrow ADD.

ADD is neither a disease nor the consequence of brain damage. Rather, it appears to be the result of inborn differences in the ability to focus and sustain attention that place the affected individuals at greater risk for failing to meet expectations in life tasks that require efficient attention. All individuals come into the world somewhere along a continuum from strong attentional abilities to weak attentional abilities, just as is the case for other genetically-based characteristics (e.g., height). When an individual falls toward the "weak" end of this continuum, there is a greater likelihood that he/she will have difficulty meeting expectations for efficient attention in some life sphere; this is the point at which the label ADD begins to apply.

Brown (1995) organizes the core symptoms of ADD into five "clusters," each of which taps a different domain central to ADD. These include:

1. Activating and organizing to work: difficulty in getting organized and started on work tasks, as well as problems self-activating for daily routines.

2. Sustaining Attention: problems in sustaining attention to work tasks, excessive daydreaming or distractibility when listening or doing required reading. Repeated loses track while reading and needs to re-read.

3. Sustaining energy and effort: problems in keeping up consistent energy and effort for work tasks, daytime drowsiness. Inconsistent work production, slacks off unless pressure is on.

4. Moodiness and sensitivity to criticism: difficulties with irritability, apparent lack of motivation. Especially sensitive to criticism, feels it for a long time.

5. Memory Recall: problems with forgetfulness and recall of learned material. Difficulty remembering names, dates or information at work.

Even though ADD has been shown in a number of studies to be a genetically-based disorder, it requires environmental expectations in order to become manifest. Depending upon the severity of the attentional weakness, the status of other skills and abilities (e.g., cognition, language, personality traits, etc.) that can be used to compensate for ADD, and the types of environmental demands that are placed on the individual, ADD can come to the fore anywhere along the life span and in any life arena (home, school, neighborhood, or work. That is to say, whether or not ADD becomes an issue in one's life depends entirely on the severity of their ADD symptoms and the demands placed on a person.

The characterizations in many quarters that ADD is a recent diagnosis, a so-called "disease of the 90's" is patently false. The symptoms of ADD have always been part of the human experience, and they have always been "diagnosed." That is, there have always been people that have been unfocused and unorganized; there have always been people who couldn't sit still, who spoke out of turn and that showed the full range of negative ADD symptoms. These people have always been diagnosed, or more correctly "judged" by peers, by family, by teachers, co-workers and employers in an entirely moral context. They were simply considered "bad" people - that was their diagnosis. What's changed is the context. Medical research has looked closely at the problem and discovered that perhaps these symptoms are a problem associated with the brain and not simply the will or the character.

Again, ADD's impact on the individual has a great deal to do with its context in society. In much earlier societies, for example, attentional weaknesses such as impulsivity and distractibility might have been valued assets when it came to exploring, hunting, and surviving. Earlier in this century, highly structured school environments, authoritarian parenting styles, and manual labor were the norm. While these facets of life may have been restrictive or limiting for certain individuals, they were likely to have helped the individual with ADD function productively without interventions, as many with the disorder react well to imposed structure, heavy discipline and expectations.

As we move toward the 21st century, however, we are increasingly putting value on individual self discipline and self control, sustained focus, and sophisticated organizational abilities at school, work, and home. Meeting these expectations without proper support is difficult, if not impossible, for individuals with weak attention. This phenomenon has played a key role in bringing ADD to the forefront in the 90's. It also underscores the complexity of dealing with ADD, raising serious questions about the direction in which we choose to go as a society.

As an individual difference, ADD can be present in people with a variety of strengths and weaknesses, intelligence levels, and personality traits. ADD appears to cross racial and ethnic boundaries. Contrary to popular belief, ADD seems to occur as frequently in females as males. It is clear that while linked together by weaknesses in attention, each individual with ADD is unique. Many individuals with ADD are extremely gifted and creative while others are burdened by co-existing learning problems, language disorders, or emotional difficulties that are independent of their attentional weaknesses.

Because our ability to pay attention modulates our interface with the environment, there are few, if any, life functions that cannot be adversely affected by ADD.

THE IMPACT OF ADD IN CONTEMPORARY SOCIETY

Over the past decade there has been an explosion of interest and research regarding Attention Deficit Disorder. As clinicians and researchers have gained more experience working with it, it has become clear that the impact of ADD on life is far greater than we ever appreciated. ADD not only can interfere with learning and behavior control in childhood, but as a critical neurobehavioral weakness that impacts on all information coming in and out of the central nervous system, it can have a profound impact on multiple areas of functioning across the life span. Research and clinical experience with ADD suggests that ADD is a significant contributor to the following serious life dysfunctions:

Health and Sociological Problems

There is a wide range of health problems which appear to be associated with ADD. It seems to be genetically linked to certain medical problems (e.g., alcoholism, addictive disorders, and Torrette Syndrome). In some individuals, ADD appears to jointly occur along with neuromaturational differences that predispose the individual to other medical problems (e.g., bedwetting, recurrent ear infections, and developmental articulation disorders).

Furthermore, if improperly recognized and managed, the biologically-based weaknesses characteristic of ADD can contribute to the development of a variety of medical problems. ADD can lead to unhealthy living patterns that foster the development of certain health problems including chronic constipation and long term bowel problems such as irritable colon and chronic diverticulitis; obesity and related problems with hypertension and hypercholesterolemia; and dental caries.

ADD characteristics can also directly lead to health problems. Research suggests that individuals with ADD who are not receiving proper treatment are at significant risk for being involved in motor vehicle violations, automobile and other accidents and, when so involved, are at increased risk for experiencing more serious injuries. In addition, clearly these characteristics significantly interfere with the ADD individual's ability to comply with recommended treatments for a variety of unrelated medical problems, placing them at risk for complications and poor outcomes.

ADD, when not properly diagnosed and treated, can result in chronic stress and recurrent failure experiences that can lead to or exacerbate a variety of mental and physical problems including depression, anxiety syndromes, hypertension, chronic pain syndromes (e.g., headaches, back pain, and fibromyalgia), immunological disorders (e.g., lupus and chronic fatigue syndrome), and premenstrual syndrome.

Finally, improperly managed ADD can contribute to dysfunctional attempts to cope with the consequences of chronic stress and recurrent failure experiences. Clearly, the impulsive adolescent or young adult with ADD who has a low self esteem

as a consequence of years of unexplained failure, is at great risk to be adversely influenced by peer pressure. When this group is mixed with contemporary societal pressures, the result is often substance abuse, eating disorders, unplanned pregnancies and venereal disease, and/or delinquent/criminal behaviors.

Addictive disorders are much more common in ADD individuals. Studies suggest that a substantial percentage of people in drug and alcohol rehabilitation programs have characteristics of ADD. Unrecognized and untreated ADD appears to be a significant contributor to our dismal record in helping individuals recover from addiction and achieve sobriety. Furthermore, significant numbers of inmates in our prisons and juvenile detention centers have characteristics and histories strongly suggestive of ADD.

At the time of its initial presentation, ADD may not clearly seem to be a serious health or social problem. However, relatively minor behavior or learning problems in childhood may represent the first signs of a problem, ADD, that may ultimately contribute to more serious problems that consume a substantial proportion of our health care and social welfare dollars.

Educational, Occupational, Economical Dysfunction

ADD is the most common contributor to learning and behavior problems in our schools. It interferes with knowledge acquisition and skill demonstration. Organizational and time management problems characteristic of ADD interfere with the development of the study skills necessary for successful navigation through the educational system. As the pace of learning and the demand for self teaching have increased in our schools, the impact of ADD and its associated attentional weaknesses have increased. Most regular classroom teachers are poorly prepared to meet the needs of the ADD student. As a result, ADD students often seek the support of costly specialized personnel and services either in or outside of the public school system. Alternatively, their needs simply go unmet; as a consequence they experience mastery deprivation which thrusts them into a cycle of failure characterized by increasing frustration, lowered self esteem and, ultimately, diminished motivation. By the time they reach the secondary grades, many ADD students are written off as lazy and are grouped with other underachieving students. Others develop defiant behaviors, "I don't care" attitudes, and tough exteriors to protect their vulnerable self esteems. Delinquent behaviors, drug and alcohol abuse, and promiscuous behaviors often follow.

Some ADD students are indeed able to maintain adequate performance through the elementary and secondary grades when provided with strong support and structure by caring and informed teachers and parents. Too often however, they experience failure at the college level as a consequence of a weakness in their independent functioning skills required to meet the increased expectations of college life. Experience suggests that ADD is a primary contributor to the increasing college drop out rates.

Other ADD students enter technical schools where, if not properly diagnosed and treated, they continue to repeat the cycle of failure. Still others turn to the military as a means to find discipline and structure only to fall short because of archaic policies that make it legitimate to have ADD in the military but against regulations to take the appropriate medication to treat ADD.

When ADD individuals ultimately enter the workplace, they are commonly problem employees. While many are skillful or talented, they often struggle to complete assigned tasks in a timely manner. They are prone to make careless mistakes. They frequently do not attend to the parts of the job that are never written in the job description. They require excessive supervision and fail to make advancements. They are chronically late and frequently absent or sick. Experience suggest they more commonly apply for disability benefits or workman's compensation. They jump from job to job. Ultimately, unemployment is far more common in individuals with untreated ADD.

Even when individuals with ADD are able to achieve satisfactorily and to obtain and maintain jobs, they often experience significant financial difficulties. They tend to spend impulsively, fail to pay their bills in a timely fashion, and rarely save. Many creative ADD entrepreneurs fail to see their ideas become reality because of a lack of planning, poor organizational skills, and financial mismanagement.

Family Dysfunction

Dealing with the chronic learning, behavioral, social, and independent functioning problems of the ADD child, who frequently looks normal, drains parents. Invariably, this leads to a roller coaster ride of guilt, fear, and enabling juxtaposed against anger, frustration, and resentment. Because ADD is a genetic problem, this scenario can be magnified by the fact that often one or both parents have similar attentional problems. As a result, these parents frequently struggle in their efforts to provide the structure and consistent discipline that are critical for the child with ADD. The set becomes more dysfunctional when uninformed teachers, physicians, or relatives intimate that the parents are either overly concerned or incompetent. Miscommunication and misperception abound in ADD families. Children with ADD have an uncanny ability to find the weak link in the parent's relationship and drive a wedge through it. Predictably, domestic violence including verbal and physical abuse is extremely common in families where ADD is present. The frequency of divorce is much greater in families where there is a child with ADD or where one or more of the spouses have ADD..

The impact ADD often has on foster and adoptive families is profound. Foster and adoptive children frequently come to be as a result of unplanned, unwanted pregnancies and/or abusive dysfunctional families. As clinical experience strongly suggests that ADD plays a significant role in both these travesties, it should be no surprise that genetically transmitted attention weaknesses are common in this population. Often, foster and adoptive parents are devastated by the fact that their love and caring cannot combat the impulsivity, distractibility, and poor response to discipline that characterizes ADD.

Clearly, wherever and whenever ADD surfaces and is not properly recognized and managed, it is antithetical to healthy functioning of the family unit.

When we combine the health, social, educational, and economic impact of undiagnosed and untreated ADD, the cost for our society is staggering. ADD is a serious problem that must be aggressively and responsibly addressed now.

RESPONDING TO THE IMPACT OF ADD
ESTABLISHING A STANDARD OF CARE FOR DIAGNOSIS AND TREATMENT

ADDA believes that one of the most critical steps in properly addressing the significant impact ADD has on contemporary society is the establishment of a standard of care for its diagnosis and treatment. While gaps exist in our knowledge about the precise etiology of ADD and controversy abounds about aspects of the diagnosis and treatment of ADD, research and clinical experience over the past several decades have been sufficient to define a beginning framework for a standard of care. The following represent our recommendations for appropriate diagnosis and treatment of ADD.

We have included in the Appendix of this document ADDA's ADD Case Management Form set. We have developed these forms for primary care physicians, schools, and other individuals who are actively involved in the treatment of ADD. The ADD Case Management Forms summarize the key components of diagnosis and treatment (described below) that ADDA feels need to be systematically addressed in order to provide quality care for ADD. Our intent is to provide an outline that guides professionals to be systematic and comprehensive when addressing ADD.

We acknowledge that there are a host of specific diagnostic tools and therapeutic modalities that may be used to complete each section. It is our hope that the set helps define a standard of care for ADD. In this regard, teams of professionals may use it to assure that they have been thorough and systematic in diagnosing and treating ADD. Primary care physicians may use it to help them manage their patients' flow through the diagnostic and therapeutic process. Finally, individuals who suspect they may have ADD may use it to help them be good consumers of diagnostic and therapeutic services.

Diagnosing ADD

Paradoxically, ADD is both over-diagnosed and under-diagnosed. Our expanded understanding about ADD and its impact on functioning across the life span has been rapidly translated to the lay public. Books, magazines, network newscasts, and television talk shows have found ADD to be a timely topic. Simplistic symptom checklists and over-identification with dramatized ADD patient stories have led many people to question whether ADD might be the reason they are experiencing difficulty in their lives. (see inset 1- Hallowell/Ratey Suggested Criteria For Attention Deficit Disorder in Adults)

SUGGESTED DIAGNOSTIC CRITERIA
FOR ATTENTION DEFICIT DISORDER IN ADULTS

Note: Consider a criterion met only if the behavior is considerably more frequent than that of most people of the same mental age.

A. A chronic disturbance in which at least fifteen of the following are present:

1. A sense of under achievement, of not meeting one's goals (regardless of how much one has actually accomplished).
2. Difficulty getting organized.
3. Chronic procrastination or trouble getting started.
4. Many projects going simultaneously; trouble with follow-through.
5. A tendency to say what comes to your mind without necessarily considering the timing or appropriateness of the remark.
6. A frequent search for high stimulation.
7. An intolerance of boredom.
8. Easy distractibility, trouble focusing attention, tendency to tune out or drift away in the middle of a page or a conversation, often coupled with an ability to hyperfocus at times.
9. Often creative, intuitive, highly intelligent.
10. Trouble in going through established channels, following "proper" procedure.
11. Impatient; low tolerance of frustration.
12. Impulsive, either verbally or in action, as in impulsive spending of money, changing plans, enacting new schemes or career plans, and the like; hot -tempered.
13. A tendency to worry needlessly, endlessly; a tendency to scan the horizon looking fo something to worry about, alternating with in attention to or disregard for actual dangers.
14. A sense of insecurity.
15. Mood swings, mood lability, especially when disengaged from a person or a project.
16. Physical or cognitive restlessness.
17. A tendency toward addictive behavior.
18. Chronic problems with self-esteem.
19. Inaccurate self-observation.
20. Family history of ADD or manic-depressive illness or depression or substance abuse or other disorders of impulse control or mood.

B. Childhood history of ADD. (It may not have been formally diagnosed, but in reviewing the history, one sees that the signs and symptoms were there.)

C. Situation not explained by other medical or psychiatric condition.

Hallowell, E.M. and Ratey, J.J. (1994). Driven to Distraction - Recognizing and Coping with Attention Deficit Disorder from Childhood through Adulthood. pp 73 - 76. New York: Random House.

Typically, this question is posed to a busy pediatrician or family doctor who is poorly informed about diagnosing and inexperienced at treating ADD. Too often, the outcome is a prescription for a stimulant medication at an inappropriate dosage schedule without any supportive counseling and minimal follow-up. Alternatively, there are probably millions of individuals with undiagnosed ADD labeled "lazy, crazy, or stupid." Both extremes are unacceptable if we are to properly address the impact ADD has on our society.

ADDA believes that meeting the needs of the people with attentional difficulties ideally begins with a comprehensive, multidisciplinary evaluation. The goals of the evaluation should include the following:

- To perform a thorough evaluation of the individual without the diagnosis of ADD as a predisposed destination.
- To clarify the impact of ADD on various life arenas
- To identify associated life stresses, skill weaknesses, physical problems, and behavioral characteristics which might jointly contribute with ADD to life dysfunction.
- To identify personality characteristics, skill strengths, and support systems that may be mobilized to help compensate for ADD
- To establish appropriate expectations for functioning in various life spheres

Because most ADD symptoms are experienced at some time by virtually everyone, the evaluating clinician has the task of ascertaining whether the individual being assessed is impaired by these symptoms substantially more than most persons of the same age or developmental level. The question is not whether an individual has ADD symptoms that most people never have, but whether that person suffers substantially more intense, more frequent, and more sustained impairment from such symptoms than most others of the same age, It is one thing if a person occasionally, when very fatigued, becomes drowsy and repeatedly distracted when reading. It is quite another matter if an individual chronically experiences drowsiness and frequent distractions almost every time he tries to read, regardless of how well rested.

At present there is no single instrument or procedure that can adequately diagnose ADD. Unlike a twisted ankle, which can be definitively diagnosed by X ray as either broken or not broken, presently ADD can be diagnosed only by a convergence of several different measures that allow an experienced clinician to determine how well the individual's symptoms fit the profile of ADD, relative to other possible diagnoses.

A competent clinical interview to access for ADD should not conclude after assessing just for ADD symptoms and their context. Adequate differential diagnosis requires at least a screening for symptoms of other possible disorders which might be causing, contributing to, or co-morbid with ADD. This does not require interrogating the person for every symptom of every possible disorder, but it does involve querying for categories of possible symptoms - for example, problems with excessive worries, moods, and drugs or alcohol - and following up on any relevant cues emerging in the interview. (Brown 1995)

Therefore, the key components of such a comprehensive evaluation should include the following:

Historical Data Collection and Review

A thorough medical, educational, occupational, social and behavioral history that includes:

Exploration of presenting problem(s)

Detailed interviewing and surveying of patient, family, school, employer, and/or agency personnel regarding the patient's temperament, developmental history, current skill level, attentional abilities, neuromaturational status, assessment of somatic functions, current and past medical history, significant stress factors present in the patient's past or current environment, attitudes, and expectations.

Sensory Testing

Vision Screening

Audiological threshold testing

Physical Examination

Assessment of growth parameters

Examination for vital signs

Standard physical examination

Neurological examination

Neurodevelopmental Testing

Assessment of neuromaturation or neurological maturity

Assessment of gross and fine motor skills

Assessment of neurobehavioral factors including state of arousal level, ability to focus and to sustain attention, cognitive tempo, vigilance, and monitoring
Survey of neuropsychological parameters including memory, cognition, and problem-solving

Neurodevelopmental Testing (continued)

Assessment of receptive language skills including semantic and syntactic aspects of language, decoding, and conceptual grouping

Assessment of expressive language skills including vocabulary, syntax, encoding, word retrieval, and communicative intent
Assessment of basic academic skills

Assessment of written expression skills

Assessment of specialized areas as indicated

Structured behavioral observation of problem-solving and stress management strategies, self awareness, self esteem, and locus of control

Case Formulation

Summarization of strengths and weaknesses

Determination of factors contributing to presenting problem(s)

Identification of diagnostic label

Treatment Planning

Delineation and presentation of goals and objectives for treatment

Requests for consultations

Selection and implementation of specific treatment recommendations

Diagnosing ADD does not necessarily require EEG's, CT Scans, MRI's blood tests or Intelligence Testing. These studies should only be undertaken when the initial comprehensive evaluation indicates their need.

It is difficult for any one professional to comprehensively diagnose ADD by him or herself, much less mange its treatment and followup. Proper health care of ADD requires the combined resources of a medically-based team of professionals. A variety of physicians can have the proper background, training, and experience necessary to lead such a team. These include selected family practitioners, pediatricians, neurologists, and psychiatrists. Other health related professionals whose expertise is frequently required to diagnose ADD include nurses, counselors, social workers, psychologists, special educators, speech/ language therapists, physical therapists, and occupational therapists.

Given the complexity of constitutional and environmental interactions, and the fact that there is as yet no objective neurological test (e.g., scan or brain wave pattern) for ADD, we believe that the diagnostic label of ADD should only be applied when

a comprehensive evaluation, as described previously, determines that an individual meets the following basic criteria:

1) Evidence of chronic inattention (i.e., low arousal, impulsivity, distractibility, short attention span, and/or poor monitoring)

2) Inattention demonstrated in multiple life spheres (e.g., school, work, home, relationships, health, etc.)

3) Objective evidence of inattention on various neurodevelopmental tests

4) Observable signs and/or history of associated nervous system difference or inefficiency (e.g., presence of excessive numbers of "soft" neurologic signs)

ADD can jointly occur with a variety of other learning, behavioral, psychiatric, neurological, and other health related disorders or handicaps and is not a diagnosis of exclusion.

TREATING ADD

ADD is a chronic medical disorder that impacts on all domains of an individual's life across the life span. Therefore, individuals with ADD ideally receive long-term follow-up and multimodal treatment. This type of treatment involves counseling the patient, working with significant people in his life, and the use of medical therapies.

Supportive Counseling

Most ADD individuals should become involved in some type of long-term counseling with a professional experienced in the management of ADD. The goals of these sessions should be to improve the ADD individual's understanding and awareness of his attentional weaknesses, to facilitate his acceptance of them, and to promote his ability to compensate for them. These visits help the ADD individual and significant others in his life set appropriate expectations, structure the environment to maximize chances for success, and define and implement specific compensatory strategies in areas where ADD is leading to dysfunction. A critical aspect of these visits should be to help the ADD patient establish a healthy daily routine for eating, sleeping, exercise, and relaxation that serves as a foundation for successful implementation of other components of the treatment plan. A variety of therapeutic modalities may be utilized to realize treatment objectives including patient education materials, feedback and debriefing, cognitive strategies, communication therapy, behavior modification schemes, and stress management techniques - including meditation and relaxation strategies - depending upon the needs of an individual patient.

Once the basic treatment plan is implemented, the ADD individual's participation in counseling sessions may decrease in frequency. Treatment should then focus on maintenance of healthy behavioral patterns, monitoring effectiveness of various treatment modalities, problem-solving when new areas of dysfunction arise and providing anticipatory guidance. Since ADD is a constitutionally-based problem, most ADD individual's should make a lifelong commitment to maintain some level of involvement in this type of counseling.

Work With Significant Others

ADDA believes that it is extremely important to involve significant others in the lives of the ADD individual in the treatment process. This may include such individuals as spouses, parents, children, school personnel, supervisors, and other health professionals who might be treating the patient.

The exact nature of this involvement may vary greatly but generally should include helping others to understand and accept ADD and the role it is playing in the patient's difficulties (e.g., marital difficulties, poor academic performance, poor work performance, and poor compliance with medical treatments).

It is common for significant others to develop highly dysfunctional, co-dependent relationships with the ADD individual. Involvement in the treatment process can facilitate the development of a more healthy, supportive relationship in which expectations are refined and the ADD individual is given the opportunity to be more appropriately responsible and accountable for his/her behavior.

Finally, since ADD itself can interfere with self observation and assessment, feedback from significant others can be highly valuable to help validate treatment outcomes.

Pharmacological Treatments

Most ADD individuals who are experiencing significant life dysfunction require the use of medication to address their underlying low arousal, impulsivity, distractibility, and short attention span. In most cases, this medical therapy should be instituted from the onset of treatment. Without the aid of medication, the dysfunctional ADD individual will be unable to effectively participate in counseling activities and/or utilize the various non-medical treatment strategies that are generated. We consider all individuals who meet the basic ADD criteria cited above and who have no contraindicators, candidates for medication therapy.

The most effective medications in the treatment of ADD children and adults are the short acting stimulants - Ritalin, Dexedrine, Dextrostat, and ADDerall. This is contrary to the belief that stimulant treatment is either inappropriate or ineffective in adults due to their age. This myth has been fostered by the unsupported notion that the onset of puberty affects the efficacy of stimulants. Furthermore, many clinicians and researchers working with ADD adults have utilized subtherapeutic dosage levels based upon recommendations in the medical literature that have no scientific basis. This, in turn, has led to an erroneous perception that stimulants are ineffective in ADD adolescents and adults.

These stimulants act on the central nervous system of ADD individuals to increase alertness, reduce impulsivity, sharpen focus, decrease distractibility, and lengthen attention span. We believe that these medications should only be prescribed when an individual meets the criteria for ADD as determined by a medically-based, comprehensive evaluation. Furthermore, we believe that stimulant medications should never be used as the sole treatment for ADD, but rather as one component of a multimodal approach.

Stimulant medication doses that are most effective vary greatly from person to person and are best determined by some type of objective, systematic procedure. Relying solely on self report by inattentive ADD individuals or inexperienced observers can result in either the use of subtherapeutic doses or over-medication.

Individuals with ADD who require medication therapy should take the medication throughout the day, seven days a week, 365 days a year. School and work are not the only places where efficient attention is important. Homework, sporting activities, automobile driving, chore completion, and social interaction are but a few of the life tasks that require efficient attention.

When used as described above, stimulants are safe medications. Common side effects such as appetite suppression and sleep difficulties can generally be managed without significant difficulty. Stimulant medication use in ADD individuals does not lead to tolerance and dependency. In fact, use of stimulants as one part of a multimodal treatment approach can actually help prevent the development of an addictive disorder in an at-risk ADD adolescent and, similarly, help the recovering ADD adult finally achieve sobriety.

Stimulant medication use should always be monitored closely with regular physician follow-up visits to monitor for side effects and maintenance of treatment efficacy. This should be coupled with supportive counseling sessions that help the ADD individual take advantage of the positive aspects of improved attention and cope with the sometimes unpleasant consequences of improved awareness of their life circumstances.

Stimulant use may be required for different lengths of time depending upon the severity of ADD and the unique factors in each person. Some individuals with ADD will require medication therapy for their whole lives. For others with less severe degrees of ADD, stimulant medication can be discontinued when the individual has demonstrated an ability to compensate for his attentional weakness without aide of the medication.

Other medications including Cylert, Wellbutrin, Clonidine, and certain Selective Seratonin Reuptake Inhibitors can be helpful in the treatment of ADD either alone or in combination with the short acting stimulants.

ADDA believes that individuals with ADD can be some of our most productive and creative citizens when they are properly diagnosed and provided with comprehensive and longitudinal treatment.

What medication cannot do

It's important to recognize that while pharmacological treatment of Attention Deficit Disorder can have a dramatic effect on an individual's ability to concentrate and organize one's thoughts, it cannot, in and of itself, change specific behaviors that have been ingrained over a significant period of time.

ADD that is sustained through adulthood often comes at a cost of years of sustained negative habits, negative self-image and destructive self-talk. There are typi-

cally many educational, school, relationship, and work-related failures that have occurred over the years. These create a "bent tree," if you will, a litany of thinking and lifestyle patterns that transcend the attentional problem itself in creating negative impact in one's life.

For example, if someone with undiagnosed, untreated ADD is chronically late, it's often because of the impulsive behavior that's characteristic of the disorder. They have a distorted time-sense, and are often irresistibly compelled to follow their impulses. When a spouse sends her partner to the store for an ingredient in a recipe that's underway, for example, the ADD individual may decide to follow other impulses that beacon to him as he drives home - a "quick" stop at a friend's house, a brief errand at the mall, and so on. This leaves his partner distressed and angry. When this person begins drug treatment for his ADD, his attentional weakness will no longer compel him to divert from his pathway home. Instead, the force of pure habit takes over, and the very same behavior may occur. To the individual with ADD, the learned behavior that was due to the disorder becomes a comfortable habit that medication cannot touch.

In short, what medication does is lay the groundwork for changes in these habits to occur, where without it, such changes may simply be impossible to produce. In that context, the importance of counseling and behavior modification cannot be under emphasized.

ADDRESSING THE IMPACT OF ADD

ADDA is committed to meeting the needs of individuals with ADD and their families and views this mission as a key to addressing the impact of ADD on contemporary society. Towards this end we are committed to and advocate realization of the following objectives:

1. To Increase Societal Awareness of ADD

The lay public should be informed about what ADD is, what causes ADD, what "red flag" behaviors might suggest ADD, how ADD impacts on learning, behavior control, independent functioning, social interaction and health, how ADD is diagnosed, and how it is properly treated. This will require massive educational efforts on many fronts. It is essential that these efforts are balanced in their perspective and should seek to dispel myths about ADD and its treatment. Too much of what has been presented to the public about ADD has either overly dramatized the positive effects of diagnoses and treatment, or alternatively, played on parents' and others' fears about medication through sensationalized stories about misuse. These extreme approaches contribute to the over-diagnosis and over-treatment of ADD in some individuals. They also create serious emotional barriers to seeking help for other individuals who really need to be diagnosed and properly treated.

2. To Increase Professional Awareness About ADD and Expertise in Diagnosing and Treating ADD

Up-to-date information about ADD should be incorporated into the basic training of all professionals who will come in contact with ADD in their professional lives. Regular continuing education updates should be provided to the same professionals who are actively working with populations that have ADD.

Educational resources should be used or developed that provide timely information about what ADD is, what causes ADD, how ADD can be identified at the earliest age, how ADD impacts on various life spheres, and how to properly diagnose and treat ADD.

Professional groups who should be targeted for these educational efforts should include but not be limited to:

- Physicians (Family Practitioners, Pediatricians, Psychiatrists, Neurologists, and other specialists who are likely to come in contact with ADD such as Gynecologists, Otolaryngologists, Gastroenterologists, Allergists, and Immunologists.)
- Nurses and Nurse Practitioners
- Physician Assistants
- Teachers and Special Educators

- Child Care Workers and Early Childhood Development Specialists
- Psychologists
- Counselors
- Social Workers
- Speech Pathologists
- Physical Therapists
- Occupational Therapists
- Employee Assistance Professionals
- Addiction Counselors
- Lawyers/Judges
- Police, Parole and Correctional Officers
- Pharmacists
- Human Resource Professionals
- Military Personnel

3. To Facilitate Interdisciplinary Communication and Interaction Among Professionals Working With ADD Individuals

Because ADD requires a comprehensive multidisciplinary approach to diagnosis and treatment and it impacts on so many areas of life across the life span, it is absolutely essential that professionals working with ADD find improved ways to interact and communicate. Unique approaches should be identified or developed that facilitate efficient and effective professional interaction regarding ADD. Linkages need to be developed between the medical community, child care, schools, work place, and the legal system among others.

4. To Increase the Amount and Quality of Basic Science and Clinical Research About ADD

Increased efforts should be made to more accurately define the etiology of ADD and its pattern of genetic transmission in order to facilitate early identification of ADD, enhance diagnostic accuracy and refine medication and other treatment modalities used for ADD. The heterogeneity of the ADD population mandates research designed to provide an expanded menu of treatment options that can be applied in a more targeted fashion to ADD individuals. In addition, this research should focus on the development of more vocational supports for ADD individuals including career guidance strategies, on-site supervision and training, and innovative compensating strategies that can realistically be implemented in the work place.

Manufacturer guidelines for stimulant medications used to treat ADD and medical recommendations that cite them should be identified and updated to be more consistent with current medical research and clinical practice.

Research should be undertaken to more clearly define the apparent contribution that ADD makes to a host of serious health, educational, and sociological problems. The results of this research should be readily translated to the lay and professional communities and to the clinical practice of professionals who are currently dealing with these problems but are unaware of the role ADD may play. Of particular import is research into the role of ADD in addictive disorders, obesity, heart disease, immunological disorders, and automobile/other accidents. Furthermore, research that explicates the role ADD plays in criminal behavior might enhance identifying at-risk individuals and improve crime prevention.

5. To Remove Health Insurance/Reimbursement Barriers to the Proper Diagnosis and Treatment of ADD

Increasingly, health insurance reimbursement policies and the movement toward managed care are creating serious barriers to the proper diagnosis and treatment of ADD. Unfortunately, some diagnostic coding books used by insurance companies to set their reimbursement policies place ADD in the "Mental/Nervous" category. This label implies that ADD is, in part, caused by environmental factors. ADD is not caused by difficult life circumstances but it certainly can create them when not properly diagnosed and managed.

Some of these manuals are out of sync with current medical knowledge. Others have been developed by professionals who may have a bias toward how ADD is categorized. Clearly, it can be to the insurance company's advantage to have ADD classified as "Mental/Nervous" because under many health insurance policies this diagnostic category means a lower reimbursement rate. Each insurance company should be mandated to properly categorize ADD as a physical problem and reimburse accordingly.

The movement toward HMO's and managed care has had serious negative implications for the diagnosis and treatment of ADD. The majority of managed care programs currently offered mandates medical treatment of ADD by primary care physicians who are often poorly prepared to meet this need and they discourage concomitant supportive counseling or set overly restrictive time limits on the same. These short-sighted decisions reflect a lack of awareness about ADD, the unique need of each ADD individual, and the chronic nature and serious long-term consequences of improperly managed ADD. These policies driven by short-term dollar savings actually promote misdiagnosis of ADD, misuse of medication, and over reliance on medication! Insurance companies should be encouraged to develop more responsive and innovative approaches to ADD. In the end, quality care of ADD is the most cost effective care.

Employers and benefits managers should be made aware of ADD and its significant ramification on health - not to mention productivity in the workplace. One of the most effective ways an employer can reduce the costs of health care benefits is by

selecting an insurance program that provides maximal incentive/reimbursement for the early diagnosis and treatment of ADD.

6. To Establish Public Policies and Legislative Initiatives That Address the Potential Negative Impact of ADD While Protecting the Rights of Individuals With ADD

As society's awareness of ADD and its impact is clarified, we anticipate that a number of difficult questions will arise:

- Should individuals with ADD be allowed to drive automobiles without proper medical treatment?
- Should individuals with ADD who are functioning well be restricted from military service if they are taking medication?
- Should ADD be taken into account in sentencing and rehabilitation of individuals convicted of crimes?
- Should individuals with ADD who take medication be restricted from obtaining pilots license?
- Should individuals with a history of ADD be prohibited from obtaining life insurance?

These questions raise issues that have broad ramifications. A dialogue about them should begin immediately so that we can avoid crisis decision-making in the future.

7. To Support Appropriate Accommodations In The Workplace And At School.

The law presently provides that employers and educational institutions make reasonable accommodations for qualified individuals with ADD which substantially effect learning and working. Accommodations may be considered part and parcel of a multimodal treatment plan for ADD that serves to mitigate the disorder's negative symptoms and improve performance to a level on par with those without ADD.

ADDA endorses the recommendations of the National Center for Law and Learning Disabilities (NCLLD), who specialize in these issues. It cannot be stressed too strongly that the process of achieving success is a two-way street. Individuals with ADD and their educators and employers should work together for their mutual benefit, and individuals with ADD should work diligently on self-accommodations to improve their performance.

The NCLLD make the following recommendations (excerpted and adapted from their literature with permission - see attachments):

A. Reasonable accommodations for employers

In general, these accommodations should provide the ADD individual with clear and specific structure in the workplace. Generally, the successful accommodations are ones which will:

1. Assist the ADD individual in organizing the tasks;
2. Reduce distractions which may lower performance;
3. Provide clear guidance as to workplace expectations, both for the "hardcore" work tasks and the more broadly social ones inherent in the workplace;
4. Provide clear and repeated work instructions; and
5. Promote understanding of this disorder.

Individuals with ADD should inform themselves. They may obtain evaluations from medical, educational, and career counseling professionals which will assist them in selecting suitable employment, designing helpful strategies, and requesting accommodations which are truly suited to their needs.

Attached are lists of possible accommodations and strategies which may serve as a general guide. As with any disability, accommodations and strategies should be tailored to the needs of each individual to maximize success in the workplace.

Sample accommodations by employer

1. Reducing distraction in the work space.
2. Giving instructions clearly both orally and in writing.
3. Breaking large tasks down into more manageable parts.
4. Providing structure in long-term tasks (checklists, deadlines for each stage, periodic meetings with supervisors).
5. Frequent and specific feedback on meeting performance expectations.
6. Extra clerical support.
7. Making accessible audio and video equipment.
8. Accommodations in examinations (extra time, quiet room, alternative format where appropriate) and in training programs (tapes, recorder, repetition, time for questions, supervised practice).
9. Modified work schedules and job structuring.
10. Reassignment to a position which is a better match for individual strengths.

Sample strategies for ADD individuals in the workplace

1. Use breaks to get physical movement/exercise.
2. Break tasks into parts and set personal deadlines for each part so that the whole task will be completed on time.
3. If talking during a meeting, use brief notes to assist in keeping focused.
4. Take notes to highlight what is needed to remember at meetings, including meetings with your supervisor. For training courses or seminars, use a tape recorder.
5. Keep work space orderly and clean to reduce distractions and help maintain focus.
6. Set aside 15 minutes at the end of the day to plan work for the next day.

7. Keep a day planner at all times. Place tasks on your "to do" list specific day.
8. Leave early for work, interviews, appointments, and meetings
9. Listen to others at meetings, and leave time before making an immediate response, especially if you are feeling argumentative or negative. Be positive and avoid impulsive responses.
10. Take "time out" if feeling frustrated or angry. Avoid interpersonal conflicts. Leave time to "cool down" and focus on what is important.

2. Accommodations for the primary and secondary school student

ADD may be a disability under three important federal statutes: the Individuals with Disabilities Act (IDEA), the Rehabilitation Act of 1973 (RA), and the Americans with Disabilities Act (ADA).

The IDEA provides special education and related services for "children with disabilities" who "by reason thereof need special education and related services." A 1991 Department of Education memorandum confirmed that children with ADD may receive services as children with disabilities under a number of categories: other health impaired, specific learning disabilities, and seriously emotionally disturbed. Indeed, the definition of specific learning disability includes ADD because it expressly includes the term "minimal brain dysfunction" which is the term used earlier for ADD. The IDEA provides for a Free Appropriate Public Education (FAPE) and for an Individualized Educational Plan (IEP).

Section 504 of the RA prohibits discrimination against students with ADD that substantially limits a major life activity such as learning. The RA applies to public elementary and secondary schools. The RA requires that students with disabilities that substantially limit a major life activity be provided regular or special education and related aids and services. The RA also prohibits discrimination against students with disabilities in private schools that are recipients of federal funds. This means that those private schools must provide to students with disabilities academic adjustments and auxiliary aids so that the courses, examinations, and activities will be accessible to them.

The ADA prohibits discrimination against students with ADD that substantially limits a major life activity. The ADA applies to all public and most private schools. Private schools are covered even if they do not receive federal funds. Religiously controlled schools may be exempt.

There are various mechanisms to enforce these statutes. Complaints may be filed with the Office for Civil Rights of the Department of Education. The ADA may be enforced by the Department of Justice as well as by private action. Schools have been held accountable; in one instance, a teacher was held liable for damages for refusing to provide adjustments clearly spelled out in an IEP.

Possible accommodations by schools

The law provides that schools provide services to students with ADD who meet the criteria. The ADA provides for reasonable accommodations and the RA for adjustments and aids. The IDEA provides for special education and related services. The 1991 Department of Education memorandum suggests that the need of most students with ADD may be met in the regular classroom with adjustments and aids. In general, adjustments or accommodations should provide the student with understanding of his or her disability, structure and reduced distractions, assistance with organizing and prioritizing, clear guidance as to expectations, and specific and repeated instructions. Possible specific accommodations are set forth below. As with any disability, particular accommodations should be tailored to the needs of the individual to maximize success in school.

1. Educate teachers and school staff concerning the nature of hidden disabilities such as attention deficit disorder and the proper techniques for interacting with students who have them.
2. Provide structure and reduce distraction in class.
3. Simplify and repeat instructions about in-class and homework expectations.
4. Give instructions clearly both orally and in writing.
5. Frequent and specific feedback from teachers.
6. Accommodations in class, including taped textbooks, tape recorders, repetition, time for questions, summary of important points, study guide, extra time for assignments, course modifications, tailoring homework assignments, breaking large assignments down into manageable parts, modified textbooks and workbooks, and priority seating in the front of the room.
7. Accommodations in examinations, including extra time, quiet room, alternative format, and opportunity to ask questions.
8. Provide "one-on-one" tutorials, adjust class schedules, classroom aides, note takers, and a services coordinator. Make accessible audio and video equipment.
9. Modification of non-academic times (e.g., lunch, recess, and physical education).
10. Use behavioral management techniques and tailor responses to the needs of students with ADD (e.g., praise for accomplishments is more effective than blame for deficiencies and structure may be constructive methods, whereas harsh penalties and criticism are usually destructive.

Possible strategies for students

Parents of students with ADD should inform themselves about the disability the medical, education, and legal aspects. They may obtain help from professionals, disability organizations, and support groups. With this help, they may assist their children in developing effective strategies and in obtaining suitable accommodations in school. As students become more mature, they should also become informed so that they may become effective advocates for themselves. Possible strategies are set forth below. As with any disability, strategies should be tailored to the needs of each student to maximize success in school.

1. Understand the disability and adopt strategies for dealing with it.
2. Sit toward the front of the class to help focus.
3. If possible to select courses, choose ones that match interests and learning style;

avoid courses in areas of great difficulty. Consider taking difficult courses during Summer or in a semester with a light load.

4. Keep a planner (assignment book or electronic scheduler) in which assignments, meetings and activities are recorded.
5. Pick a quiet and comfortable study place and keep it clean and orderly to reduce distraction. Schedule study periods and take breaks to get physical movement and refreshment..
6. Break homework tasks into parts and set personal deadlines for each part so that the whole task will be completed on time.
7. Set aside 15 minutes at the end of study time to plan the next day.
8. Ask questions if unsure about an exam question; and if still unsure, put down all the information you know that relates to the question some credit will be applied and the teacher will know that effort was made.
9. Use strengths to promote success by suggesting a project you can do in place of one that's assigned and that may be particularly difficult, or do extra credit projects (e.g., seek permission to construct a model or produce a video instead of writing a long paper).
10. Take "time out" if feeling frustrated or angry. Spend time "cooling down" and focus on what is important. This will help to avoid conflicts with teachers and fellow students.

2. Accommodations for the college student

College students with ADD can be successful in the learning setting. College disability services staff, faculty, family and other social supports, combined with advocacy by the college student with ADD are key elements in achieving success.

Legal rights of the student with ADD

ADD which substantially limits a major life activity such as learning is a disability under two important federal statutes that apply to most colleges: the Rehabilitation Act of 1973 (RA) and the Americans with Disabilities Act (ADA).

Section 504 of the RA prohibits discrimination against otherwise qualified students with ADD that substantially limits a major life activity such as learning. The RA applies to all colleges that receive federal funds; all public colleges and most private colleges. The RA requires that students with disabilities that substantially limit a major life activity be provided with academic adjustments and auxiliary aids so that the courses, examinations, and activities will be accessible to them.

The ADA prohibits discrimination against otherwise qualified students with ADD that substantially limits a major life activity and requires that those students be provided with reasonable accommodations. The ADA applies generally to public and private colleges, regardless of whether or not they receive federal funds.

Many colleges are offering programs and/or support services for students with learning disabilities and ADD. Most require standardized admissions tests SAT or ACT but some waive these tests as an accommodation in the admissions process.

Students with ADD and/or learning disabilities who take standardized admissions tests may be eligible for test accommodations, e.g., extra time, breaks, alternative format. To establish eligibility, the disability must be documented in accordance with the requirements of the testing service.

Students with ADD may choose if and when to disclose their disabilities. If admissions and/or test accommodations are not needed, a student may elect to disclose the disability after admission. Remember, if the college is not aware of the disability, the college would not be required to provide accommodations.

In disclosing disabilities and requesting college accommodations, the student should consult with professionals to determine what documentation to provide to the college. The particular accommodations that a student may need is an individual matter. Some students may have one or more learning disabilities in addition to ADD. The request for accommodations should take into account how the disabilities impact on the student's learning. If a student has questions about confidentiality of information regarding the disability, he or she may consult with independent professionals and/or college personnel.

Colleges must provide legally required services at no additional charge to a student with a disability. Generally, the college must provide services necessary to make courses, examinations, and activities accessible to a student with a disability but is not required to provide remedial services to improve the skill level of the student in the area of his or her disability. For example, test accommodations and note takers would be provided free of charge to students in need of those accommodations. Colleges may charge supplemental fees for services that are over and above legal requirements. For example, a fee may be charged for the services of a remedial reading tutor.

There are various mechanisms to enforce these statutes. Complaints may be filed with the Office for Civil Rights of the Department of Education. The ADA may be enforced by the Department of Justice as well as by private action.

Possible accommodations by colleges

In general, accommodations should provide the student with structure and reduced distractions, assistance with organizing and prioritizing, clear guidance as to expectations, and specific and repeated instructions, as needed. As with any disability, particular accommodations should be tailored to the needs of the individual to maximize success in school.

Possible specific accommodations are set forth below.

1. Provide structure and reduce distraction in class.
2. Simplify and repeat instructions, as needed, both orally and in writing.
3. Give frequent and specific feedback from faculty and disability services staff.

4. Accommodations in courses may include: priority registration, reduced course load, taped textbooks, tape recorders, course modifications, tailoring assignments, modified textbooks, priority seating in the front of the room, study guide, and summary of important points.
5. Accommodations in examinations may include: extra time, quiet room, alternative format, and opportunity to seek clarification.
6. Allow course substitutions to fulfill certain requirements, e.g., for foreign language and mathematics.
7. Offer as electives alternative learning style ;courses, e.g., history through film and internships to emphasize hands-on learning.
8. Educate the student regarding ADD, coping strategies, and advocacy techniques.
9. Encourage the use of support groups, counselors, and advisors to assist with academic, career, and other issues.
10. Review rules and expectations and use behavioral management techniques as needed.

Possible strategies for students

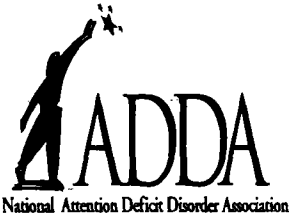
As with any disability, strategies should be tailored to the needs of each student to maximize success in college. Possible strategies are set forth below.

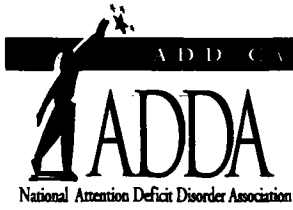
1. Continue to become educated about ADD, strategies and accommodations that might be useful, and legal rights and advocacy techniques.
2. Sit toward the front of the class to help focus.
3. Use note takers or a tape recorder in classes.
4. Take time to get to know faculty and disability support staff, and seek them out to request any needed assistance. Seek help as soon as you experience difficulties. Consider working with a counselor or advisor to help learn coping strategies.
5. Keep a planner (assignment book or electronic scheduler) in which assignments, due dates for papers and projects, your plans for completion, dates of quizzes, mid-terms and final exams, and plans for study periods are recorded.
6. Pick a quiet and comfortable study place, schedule study periods, and take frequent breaks to get physical movement and refreshment.
7. Set aside 15 minutes at the end of study time to review progress on various projects and to plan the next day.
8. Select courses that are high interest and a good fit for your learning style. Consider taking a reduced course load. If possible, request course substitutions to fulfill requirements that pose great difficulty due to the disability.
9. Request needed accommodations in advance in courses, examinations, and activities.
10. Ask questions about assignments or an exam questions not understood; if still unsure, note the question and then proceed to complete the test to the best of your ability and understanding.

IN CONCLUSION

Perhaps twenty million people or more in the United States alone live with Attention Deficit Disorder. Each one counts on Congress to discover the facts about ADD and to do the right thing. To act to vigorously protect the rights of each American with ADD to seek an appropriate education, to work productively in the workplace, and to seek and receive appropriate medical treatment without undue and unreasonable restraint by the insurance industry. In this testimony, we have sought to explore the basics points of consideration. We have suggested solutions to reduce misdiagnosis and curb inappropriate prescriptions of Ritalin and other medications. ADDA remains strongly committed to advocate for the needs of individuals touched by Attention Deficit Disorder, and as such, count on your thoughtful consideration of the issues we have placed before you.

ADD CASE MANAGEMENT FORM PACK





ADD Case Management Form **1**

NAME _____
DATE OF BIRTH _____
RECORD # _____
DATE OF EVALUATION

▶ Identifying Information

Parents/ Spouse _____ School/Employer _____
Address: _____ Referral Source: _____
Phone: _____ Family Doctor: _____

Presenting Problems/Chief Complaints

ADD CASE MANAGEMENT FORM 3

ADDA
National Attention Deficit Disorder Association

NAME _____
DATE OF BIRTH _____
RECORD # _____

▶ Physical Assessment

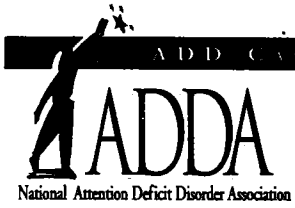
Areas surveyed (✓)

Vital signs	☐	Neck	☐
Growth Parameters	☐	Chest	☐
Nutritional status	☐	Lungs	☐
Hygiene	☐	Heart	☐
Vision screening	☐	Abdomen	☐
Audiological threshold	☐	Genitalia	☐
Head	☐	Skeletal structure	☐
Eyes	☐	Skin	☐
Ears	☐	Neurological	☐
Nose	☐	Gross Motor	☐
Dentition	☐	Fine Motor	☐
Pharynx	☐	Soft Neurological Signs	☐

Other

_____ ☐
_____ ☐
_____ ☐

Notes/Findings



ADD Case Management Form **2**

NAME _____

DATE OF BIRTH _____

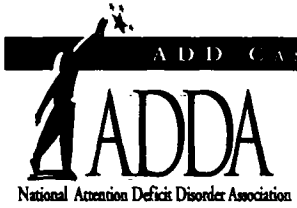
RECORD # _____

▶ Background/History

Areas surveyed (✓)

Medical History		Educational History		Social Behavioral History	
Pregnancy	☐	Preschool	☐	Developmental Attainment	☐
Newborn	☐	Elementary	☐	Temperamental Style	☐
Past Illness	☐	Secondary	☐	Independent functioning	☐
Surgeries	☐	College	☐	Parental Management	☐
Accidents/Injuries	☐	Technical	☐	Response to Discipline	☐
Review of Systems	☐	Current achievement level	☐	Delinquent Acts *involvement with the law*	☐
Drug & Alcohol Use	☐	Special Services	☐	Family History	☐
Somatic Functions	☐	Family History	☐		
Sexual Behavior	☐				
Family History	☐				

Notes/Comments:



ADD Case Management Form **4**

NAME _____
DATE OF BIRTH _____
RECORD # _____

▶ Neurodevelopmental Survey

Areas surveyed (✓)

		Bt whom (referred to)
Attention	☐	_____
Memory	☐	_____
Cognition	☐	_____
Problem-solving	☐	_____
Receptive Language	☐	_____
Expressive Language	☐	_____
Mathematics	☐	_____
Reading	☐	_____
Written Expression	☐	_____

Comments:

ADD Case Management Form 5

ADDA
National Attention Deficit Disorder Association

Name _____
Date of Birth _____
Record # _____

▶ Case Formulation

ADD diagnostic criteria met ☐ ADD diagnostic criteria NOT met ☐

Other identified contributors/diagnoses _____

Areas of strength _____

Comments:

ADD Case Management Form 6

ADDA
National Attention Deficit Disorder Association

NAME _____
DATE OF BIRTH _____
RECORD # _____

▶ Recommendations

Strategies suggested (✓)

Stimulant medication trial testing	☐	*Medication* _____ *Dosage* _____
Stimulant medication clinical trial	☐	*Medication* _____ *Dosage* _____
OTHER medications		
	☐	_____
	☐	_____
	☐	_____
Additional testing		
	☐	_____
	☐	_____
	☐	_____
Supportive Counseling	☐	*By whom:* _____
School meeting	☐	
Special Services	☐	
Work accomodations	☐	
Support Group	☐	

REFERRAL
For comprehensive evaluation ☐ _____

Other strategies

Mr. SHAYS. Thank you, Mr. Morris. Ms. Gill.

Ms. GILL. Mr. Chairman and members of the subcommittee, thank you for the opportunity to appear before you today. I speak to you as the parent of Brian and Michael, 17 and 12, who both have ADD, and as a member of the northern Virginia Chapter of CH.A.D.D. I would like to share with you my experiences as a parent of two children with ADD and tell you about the steps that Virginia has taken to lead the Nation in addressing the educational needs of children with attention deficit disorders.

I have personally seen what an amazing difference an appropriate education can make in the life of a child with disabilities. It is with a great deal of pain that I remember the early years of my 12-year-old son, Mike's, life. Mike's difficulties began in preschool. I dreaded picking him up each day because the teachers or the other children would confront me with details of his rude behavior that day. He was a hated child, and nothing that my husband or I did seemed to help.

His behavioral problems did not improve in kindergarten. A student intern, one day, was given the task of writing down everything that he did wrong that day. I received a list of 22 negative acts, which included not sitting in his seat, to not following directions, to making inappropriate noises. All of this occurred in only a half day.

When Mike was in the first grade in Fairfax County, he was recommended for psychological testing, because the staff suspected that he was emotionally disturbed and that he should be in a self-contained classroom. The tests revealed visual and motor deficits, a reading disability, and possible ADD. He was given a full medical and neurological examination later which confirmed the diagnosis of ADD. Behavioral counseling and medication was recommended. Shortly thereafter, Mike began to blossom in school.

Mike was found eligible for special education because of his ADD and learning disabilities. He had difficulty with written and expressive language, and had trouble concentrating, following instructions, and staying on task. In the fourth grade, he still was not able to write a coherent report. His special education teacher educated his other teachers about ADD, and we all worked together to help him succeed.

This child, who was thought to be emotionally disturbed and recommended to be separated from his regular peers, is now, according to his principal, the most popular boy in the sixth grade. Academically, he recently received a Presidential academic and athletic award and the top math award. For this, I am thankful to his trained teachers and the IDEA special education program.

My other son's story is much different. Brian is a high school junior this year and was an A–B student with no behavioral problems in school. In his freshman year, he was no longer able to keep up with his school work, and his grades dropped steadily to C's and D's. He was considered to be unmotivated and lazy, and purposely not trying. It was not until we finally had him tested this year that we found out that he has a similar reading disability as his brother, and that he has the unhyperactive form of ADD. This often is not evident until the later grades, when the work becomes more difficult.

He qualified for special education services and his treatment plan includes educational interventions and medication. Progress was seen during this last quarter. He scored 96 on his final psychology exam and his teacher said that he is working harder in class.

I am very fortunate to live in the Commonwealth of Virginia. It was one of the first States to have an ADD task force to add ADD to its education regulations and to implement a number of effective and innovative strategies for assisting ADD students.

In 1996, the Virginia General Assembly passed legislation making it mandatory by the year 2000 for teachers to receive training in ADD before they can be licensed. Although Virginia has accomplished a great deal legislatively, we are not—we are finding that the elementary schools far surpass the secondary schools. We often see that children who have made out well in elementary schools, once they reach the middle schools and high schools, they find the schools to be less accommodating in academic failure, as well as behavioral problems would emerge.

My fear is that my son, Michael, is going into middle school. Will he receive the services in the middle and in the high school that he has received in the elementary school?

I thank you for giving me this opportunity to talk about my sons and to also let you know how grateful I am to IDEA and to the commitment of the State of Virginia.

[The prepared statement of Ms. Gill follows:]

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to appear before you today. I speak to you as the parent of Michael and Ryan, my sons who both have attention deficit disorder (ADD), and as a member of the Northern Virginia Chapter of Children and Adults with Attention Deficit Disorders (CH.A.D.D.). I would like to share my experiences with you as the parent of two children with ADD. I would also like to discuss the steps my home state of Virginia has taken to lead the nation in addressing and recognizing the needs of individuals with ADD and to educate its school personnel about attention deficit disorders.

I have personally seen what an amazing difference an appropriate education can make in the life of a child with disabilities. It is with a great deal of pain that I remember the early years of my son Mike's life. Mike's difficulties in school began when he entered preschool. I dreaded picking him up everyday after school because the teachers and other children would confront me with details of his rude behavior that day. He was a "hated" child and nothing my husband and I did seemed to help. At home, we tried to correct his inappropriate behavior with time outs, taking away privileges and by discussing his behavior with him at length. Despite our efforts to get through to him, nothing seemed to work.

Mike's behavioral problems did not improve as he entered kindergarten. To give you an example of what I went through, a student intern was assigned to write down everything my son did wrong in his kindergarten class one day. The list I was given included twenty-two negative acts which ranged from not sitting in his assigned seat to hitting other children to not following directions to making inappropriate noises. All these behaviors occurred in only a half-day! I was instructed to speak to Mike about each of these inappropriate acts. I was too overwhelmed to do anything. Those days were filled with anger, frustration and tears.

When Mike entered the first grade at Lees Corner Elementary School in Fairfax County, his teachers suggested psychological testing because they suspected that he was emotionally disturbed. Tests revealed visual and motor deficits as well as a reading disability. The school counselor suspected that his behavior might be attributable to attention deficit disorder (ADD), a disorder her own two sons had. She recommended additional testing by a developmental pediatrician who gave us a preliminary diagnosis of ADD. A full medical and neurological assessment confirmed her diagnosis. She developed a treatment plan that included behavioral counseling and medication. Additionally, my husband and I attended short term counseling with Mike's teachers. Shortly thereafter, Mike began to blossom in school.

When Mike was tested in school, he was found eligible for special education services due to his ADD and learning disabilities. He had a great deal of difficulty with written and expressive language. In the fourth grade, he was still unable to write a coherent report. In addition, he had trouble following oral instructions, concentrating and staying on task. He continued to receive special education services until the end of the sixth grade. His teachers were knowledgeable about ADD and we worked together to assist him with his school work.

Mike just completed the sixth grade this past month. This child, who was considered "emotionally disturbed" and recommended for a self-contained classroom, has turned out to be, in the words of his principal at Lees Corner School, "one of the most popular boys in the sixth grade." He "graduated" from special education this past January. Last month, he received the Presidential Academic Award, the class math award, and an award for receiving the Presidential Athletic Award three years in a row. Mike is an example of a child with ADD who, with an appropriate education provided by IDEA, has become successful academically and socially.

My other son, Ryan, was recently diagnosed with ADD without hyperactivity. In contrast to his younger brother, Ryan was well-behaved in school. He was an A-B student until his freshman year in high school, when his grades began to drop. Each semester, they got lower and lower, until he was earning C's and D's. His teachers told us that he was lazy and unmotivated and saw his refusal to do work as a behavioral problem. In 1995, during his sophomore year, he was diagnosed with depression and treated medically. We suspected that Ryan's difficulties were caused by more than depression and during his junior year, we had him privately evaluated. He was diagnosed with ADD without hyperactivity, along with a previously undiagnosed reading disability. After the private evaluation, his school followed up with additional tests that confirmed his diagnosis. He was placed on a treatment plan that included educational accommodations and medication. During the last few months of this past semester, his grades had already begun to improve. After a semester of near-failure in psychology, he scored a 96 on his final exam! He has qualified for services under IDEA and will begin receiving special education this fall as a high school senior.

Beyond an appropriate education, Mike benefited from having teachers who understood how to educate children with ADD. The Commonwealth of Virginia is one of the leaders in the nation in promoting training for educators in ADD. Virginia was one of the first states to add ADD to its education regulations and has implemented a number of effective and innovative strategies for assisting students with ADD. In 1996, the Virginia General Assembly passed legislation making it mandatory by the year 2000 for teachers to receive training in ADD before they can be licensed. The Assembly also

passed a resolution which recommends that school board members, principals, and educational staff be trained in ADD. In 1995, the legislature passed another resolution which recommended that teachers and administrators assist children with ADD in order to reduce the number of children with the disability who drop out of school. William C. Bosher, Jr., the Superintendent of Public Instruction, noted in a memo to Virginia school districts that it is important to serve children with ADD, due to the alarming national statistics which indicate that students with ADD are at a high risk for problems including underachieving in school, dropping out of school and attempting suicide.

Although Virginia has accomplished a great deal legislatively, Virginia's elementary schools far surpass the secondary schools in serving children with ADD. Many children with ADD who are successful in elementary school find middle school and high schools to be less accommodating, and we have seen academic failure as well as behavioral problems reemerging. My son Ryan's case provides an example of teachers who are unwilling to see increasingly poor grades as the sign of a disability. In 1992, Fairfax County established an ADD Task Force to study this issue, and I was asked to join that group. This past January, Fairfax County school personnel, CH.A.D.D. professional members and CH.A.D.D. parents joined together to provide a workshop on ADD to over 250 secondary school guidance counselors. This coming fall, the county will offer a fifteen class series on educating the ADHD child. A separate series will be offered for both elementary and secondary teachers. The Task Force is hoping to develop a training institute in ADD for principals, assistant principals and guidance directors. Our children's success depends on a commitment to providing the resources necessary to train school personnel in ADD so they can help children become successful.

Mike will enter middle school this coming fall and will face new challenges. The first year in middle school is typically very difficult for children with disabilities. I have seen my son go from a child with academic and behavioral problems to a successful, well-adjusted teenager thanks to the proper identification and an appropriate education. I know that my son Ryan, will be able to experience success, after receiving the proper evaluation, treatment and educational accommodations. I hope that IDEA and the State of Virginia can continue to provide the services children with ADD need in order to become successful, so that other families can benefit from this program just as my family did.

Mr. SHAYS. Thank you very much. Mr. Barrett.

Mr. BARRETT. Mr. Morris, I was intrigued by your testimony as an adult who was diagnosed with ADD. If you would be willing, could you tell me how you came about to be tested for it?

Mr. MORRIS. Yes. Actually, it's instructive for a lot of people. As I mentioned in my testimony, one feature of my disorder was memory. And this has been something that had been going on since the time I was a child. Well, what happens with attention deficit disorder is, of course, the longer—as your life progresses and people become more demanding, you have to read certain things that perhaps you don't want to read and you have to remember items in college and so on, this really begins to show itself up in spades.

And it happens that a relative of mine came down with Alzheimer's disease. And this got me thinking about what my problem was: Could I have Alzheimer's disease? So I went to the University of Michigan Neurology Clinic to be tested. We talked about the various symptoms that I was having.

The doctor said, you know, if this were the mid-1800's, you wouldn't have a problem. I said, why is that, Doctor. Well, in the mid-1800's, you know, you didn't have a lot to remember. You were vice president of a company and you have another enterprise on a side, and you fly an airplane, you have too much to think about.

I said, Doctor, when was the last time you forgot your wife's name.

He said, look, what we'll do is we'll put you through a series of pretty intensive tests, which I went through. It was an 8-hour test. I sat and worked with computers and worked with blocks and worked with all kinds of stories and so on. The doctor who I was supposed to get together with in the following 2 weeks to go over the results of the test instead called me up the next morning and said, we'd like you to come in right away because we'd like to have you take an MRI and rule out a brain tumor. There's something going on here.

Interestingly, I was elated, because maybe there was a reason for what was going on. I went through the MRI. It was negative.

The doctor then said, well, basically, you're going to have to go down the hall and talk to a psychiatrist. It must be stress related.

To make a long story short, I ended up with somebody who was looking at my chart. I had a brother, also, who was ADHD and this person happened to be aware of that person. It was called, as we uncovered earlier, minimal brain dysfunction at that time.

She was going through my chart on the second time we got together. And she stopped me in mid-conversation. She says, you know, I know exactly what you have. I know I'm not qualified to treat it. I'm going to send you to somebody else who is, but you have something called attention deficit disorder. And the rest is history.

The actual diagnosis itself put things in perspective that had been awry my entire life.

Mr. BARRETT. And what type of treatment did they have for you then as an adult?

Mr. MORRIS. It's exactly the same, actually, as a child. I started on a trial of Ritalin. I'll say one other thing in terms of diagnosis. One of the things that brought me, after the first doctor said, you

need to go see a psychiatrist, I was very resistant to that. I saw a segment of "20–20," ABC's "20–20" on attention deficit disorder, and saw myself sitting in one of the roles of the people who were portrayed there.

And I started on a course of Ritalin and learned along the way that medication, whether for a child or an adult, and particularly an adult is not a magic bullet. And we started to combine all kinds of behavioral therapy. I met Mr. Daytimer. And it was a very interdisciplinary kind of treatment.

Mr. BARRETT. So do you continue to receive Ritalin now?

Mr. MORRIS. No, I don't take Ritalin. I take another medication. And, again, in my testimony, I mentioned that, you know, if you listen to the media around you, the only drug you know is called Ritalin. There are many other medications, Cyler, Dextrine, Adoral. Adoral is the medication that I take.

Mr. BARRETT. It's similar to Ritalin.

Mr. MORRIS. Correct. They are psychostimulants.

Mr. BARRETT. Ms. Gill, you made references to the educational system in Virginia helping out your children. Do you attribute that more to the State support, to the Federal support through the IDEA legislation? What do you think was most helpful for your children?

Ms. GILL. In regard to the beginning of the programs for my child with ADD, when the policy statement came out in 1991 stating that attention deficit qualified other health impaired to receive special education services, that is when the services began in Fairfax County. When that statement came out, it had a major, major impact on changing the educational system for children with attention deficit disorder.

Our State, though, had already been urging the education departments to provide these services. But it was not until the IDEA gave this qualification under other health impaired, that the schools felt impelled to begin providing services.

Mr. BARRETT. So you're referring to the Federal Department of Education policy statement?

Ms. GILL. Yes.

Mr. BARRETT. As I indicated in my earlier question of an earlier panel member, the IDEA legislation has passed the House and is now sitting in the Senate. It's in question as to whether it will go to the President. Do you think that that would have a detrimental effect for programs like your children's experiences, or do you feel confident that the States would continue these programs at this time?

Ms. GILL. I think it will depend on the States.

Mr. BARRETT. I'm sorry?

Ms. GILL. I think it will depend on the States.

Mr. BARRETT. Do you feel in Virginia that Virginia will continue to do so?

Ms. GILL. I feel comfortable that Virginia will. I'm not sure that the other States will provide the services as well as Virginia does.

Mr. BARRETT. One of the things that we've also heard testimony about and I've had questions about is the concern with the drugs, with Ritalin and the other drugs that are similar to that, and the concerns from the Drug Enforcement Agency that maybe there is

too much reliance on them. I don't know if I'm stating that correctly, but maybe I'll ask you, Ms. Richard, what your feeling is on that.

Do you think that there is too much reliance on the prescription type of treatment as opposed to behavioral building treatment?

Ms. RICHARD. Well, CH.A.D.D. sees medication as one part of an individualized treatment plan. It's not always part of every plan. CH.A.D.D. has advocated from the very beginning for treatment protocols that involve educational and family interventions, possibly counseling for children of the family, as well as medication when indicated and prescribed by a qualified physician.

Mr. BARRETT. Mr. Morris, any thoughts on that?

Mr. MORRIS. I think absolutely. I think most research has shown that, particularly in adults—I won't even limit it to adults. That in most individuals with moderate to severe forms of attention deficit disorder, that medication is pretty much indicated.

If I may make an analogy, it's very much as if you needed glasses. There is no way that you're going to learn how to read the printed page if you can't—if the page is just a blur. At the same time, just because you get the glasses doesn't mean that you're going to learn how to read. So the two are very much intertied.

And the problem that we have today is that many people consider it, again, a magic bullet. That you're just going to be able to put those glasses on and the rest will go away. Typically, it doesn't happen that way.

Mr. BARRETT. Ms. Gill, do you think there's a tendency to say, here, take these two pills and you'll be better in the morning?

Ms. GILL. Unfortunately, I think that there is a tendency within the medical profession sometimes not to do a total evaluation and assessment. And this is extremely necessary. I would be against giving just writing a prescription out. And I know that it does occur where a child is brought in for a 15-minute evaluation and handed a prescription. And I know that CH.A.D.D. and ADDA are very strongly against things like that being done.

Mr. BARRETT. Thank you.

Mr. SHAYS. I have really appreciated the testimony of both panels and find myself with lots of different questions. Ms. Richard, you have two children?

Ms. RICHARD. Yes.

Mr. SHAYS. And you mentioned—did they both get diagnosed at the same time?

Ms. RICHARD. They were about the same age. Well, one was 4 and one was 6, or they were approaching ages 4 and 6 at the time. And, actually, I often tell the story that our pediatrician and his wife used to sit in back of us in church and it was giving them a lot of opportunity to observe the Richard boys in a naturalistic setting.

But, in any event, at the time the boys were these ages. And, particularly, in our younger one, the symptoms of hyperactivity had sufficiently manifested themselves everywhere. We were advised by our pediatrician to seek some comprehensive assessment for both children. In general, they were both seen by a licensed psychiatrist in the area of child and adolescent psychiatry, a pediatric psychologist, as well—and we also a neurology consult on one of the chil-

dren, who also some symptoms that we were concerned about, as well, to look into some neurology issues.

So the process of identification was not something that was short. It was one that took place over time, I think, very carefully. And, also, I must say with great support from our primary care provider, Dr. Rouse, the pediatrician.

The children had very different personalities, I should also say. That, like Maureen, the children didn't necessarily present the same if you had met them.

Mr. SHAYS. Mr. Morris, I was going to ask some of the questions that Mr. Barrett asked, because obviously I'm intrigued. Sometimes I think my generation tends to sometimes think, my God, I was like that in school, too. And you wonder how you survived without the assistance that—quote, unquote assistance that some children have today.

And I guess the question that I wanted to ask you is this: I'm a little unclear as to your point basically in terms of your receiving the diagnosis. That was a relief to you. But then you thought, what, that once you had been diagnosed, the solution would come quickly?

Mr. MORRIS. Well, I think I didn't know at that point. I was completely unfamiliar with ADD. As a matter of fact, when I got the diagnosis, there was really only one book on the market. I think it was attention deficit disorder in adults by Lynn Weiss. And, you know, it was an emotional thing. Yeah, you go through your life thinking to use the title of a well known book, you think you're lazy, stupid or crazy. You think there is genuinely something wrong with you that is completely out of your control.

And the way this is manifest is in self-image. And if I could expand a bit, this is what happens to children who are undiagnosed. What happens is—and I can tell you from personal experience because I had a brother who had attention deficit hyperactivity disorder, and many of these kids have much different problems than I had. I had the non-hyperactive version, so I was just a kid who was involved in a lot of things and flying around from thing to thing.

You have kids who have attention deficit hyperactivity disorder and you have genuine anti-social things happen in the classroom. And as a result, these kids get treated as delinquents and they tend to oblige you by becoming them if they're not given proper role models and intervention.

And I can tell you this from personal experience, because my brother, who was diagnosed when he was 6 years old and with minimal brain dysfunction——

Mr. SHAYS. That was the diagnosis at the time.

Mr. MORRIS. And then it was changed to hyperkinesis a few years later. Led a life that was pure carnage and was ridiculed and shamed and sent to the principal's office on a daily basis. And he became a delinquent. And when he was 13 years old, my parents took him to a psychiatrist. And they said Marty would either be in jail or dead by age 21. I'm sorry to say that he ended up dying at age 21 of an overdose. And it had nothing to do with his ADD. It had to do with a completely destroyed self-concept.

And for the people that don't die at age 21, the ones that go on to try to find their way in the world, the vestiges of not getting properly diagnosed and treated as a child go on and on. And whether in major ways, when the ADD is severe, or minor ways, when the ADD is not so severe, it lasts a lifetime in the majority of cases.

Mr. SHAYS. Ms. Gill, I'm going to ask a question somewhat related to my question of Mr. Morris, because he was diagnosed as an adult. One of your children was diagnosed later than the first. The older—one was in high school at the time, is that correct?

Ms. GILL. Yes, just this year.

Mr. SHAYS. Now, am I to make the assumption that if you have the disorder it is apparent at a very early age and it was just left undiagnosed; or can it appear later in life?

Ms. GILL. The unhyperactive form can be masked, especially if you have a very bright child who can make it.

Mr. SHAYS. So the answer is yes, basically, that you make the assumption that he had the disorder earlier?

Ms. GILL. Yes. Yes, he had it earlier. But when the work became complex, that's when it started to become evident and he couldn't hold it together.

Mr. SHAYS. I'm tempted to get the first panel back here to diagnose our witnesses here.

Ms. GILL. I think that Dr. Jensen did mention this during his testimony. He did mention something about the unhyperactive form. It's not infrequent that that form is not diagnosed until later.

Ms. RICHARD. I think I'd like to add to that. When my 6-year-old was identified, I think it was because his hyperactive brother led the way. And, indeed, the things we had were such things as the report of a first grade teacher who explained that the reason that my son couldn't read so well was because he sat underneath the table during reading group humming the Star Spangled Banner.

And these were things that had to be considered by someone more expert to interpret that might be going on with that child.

Ms. GILL. And my son, also, my older son, they told me that there was no way he could be learning disabled because he got A's and B's in seventh and eighth grade. And yet the testing results showed a very evident learning disability and reading problem. So he was able to mask it for all of those years, but he fell apart in his freshman year.

We had originally thought that he had depression. And he was treated for depression. But even with the successful treatment for depression, he still exhibited cognitive problems that persisted until this year. Each one of his report cards got steadily worse, from freshman year, even with treatment for depression. That's when we did the full range of educational and psychological batteries and that's when the disabilities for ADD, as well as the learning disabilities showed up.

But I have been involved for 7 years and I did not know that my son had it.

Ms. RICHARD. I think it's important to recognize that among the factors that protect children with these disabilities, although there are these protective factors, such as very loving and dedicated par-

ents, truly concerned teachers and good environments, nonetheless this may allay diagnosis of children who are not as obvious as the hyperactive ones.

So we do a very good job in terms of protecting our children. On the other hand, we may also in some respects be keeping them from identification that's critical to their future success.

Mr. SHAYS. The implications of this issue are mind boggling. I mean, you could go to your penal institutions and you could do testing there and you could come up with conclusions. I mean that in a positive way, because of the comment I'm going to make now. I mean, California never ceases to amaze me in the ways that they find someone not guilty of a crime. One of them was the Twinkie defense in California when a supervisor killed one of his other supervisors.

But, having said that, I'm struck with lots of different reactions.

Do you have any other comments you want to make? We could go on for a while.

Mr. MORRIS. I think I could make a couple of comments. First of all, yes, is there a trend in America for, I'm another victim? Yes, absolutely. But I don't put attention deficit disorder in that category.

Genuinely diagnosed with appropriate people who know what they're talking about, attention deficit disorder. Is it, as Dr. Hollowell likes to call it, a seductive diagnosis? Absolutely. Imagine you're someone at work, and the rest of your life is fine, but somehow you can't seem to get your reports in on time to your employer. How interesting is it to read a Time magazine and think, you know, I could tell them the reason for that is I have attention deficit disorder.

It's a seductive diagnosis, but that doesn't mean it's accurate in everyone who claims they have it.

Mr. SHAYS. I guess you actually triggered this comment. I'm left with an unresolved question, young girls tend not to be diagnosed as much as young boys. I make an assumption that wealthier children tend to be diagnosed more than children who aren't as wealthy, and suburban kids more than urban children. I'd like to try to get an answer to that. I don't think you all have that answer.

But I am struck then with the fact that, given the treatment may involve chemical, but also behavioral, efforts. I mean, in other words, I'm struck with the fact that you have to work at this, Mr. Morris.

In other words, the parents have got a major role to play in this process. And it doesn't enable them with this diagnosis to walk away and say, now, I understand, it's not my fault. Not that I want people to think of it as their fault, but they've got some accountability, some role to play in the healing process.

Mr. MORRIS. Absolutely. Absolutely. And this is in many ways a very eye-opening experience for a lot of people.

Mr. SHAYS. It's a what experience?

Mr. MORRIS. It's a very eye-opening experience for a lot of folks who have—or are diagnosed with attention deficit disorder. A lot of people go to a physician. They begin on medication and they think, presto, life is going to change. And, indeed, probably for the

first few weeks, the what we call the placebo effect of the medication does make everything wonderful.

But the problem with adults and young adults in particular manifestations of attention deficit disorder is that it's a bent tree. What you have is someone who is diagnosed when they're 25 or 30 or 50, or even 16, is a lifetime that is spent developing habits that are counterproductive, developing relationships that are problematic, developing ways of human interaction that follow them their entire life.

So what happens again in the analogy that I posed where you put the glasses on, all of a sudden, you can see what's going on, but you've got a lot of work to do in catching up.

Mr. SHAYS. That's a good analogy. Would either of you or all three of you be able to respond to whether there's a protocol that does not involve drugs, that you're diagnosed with ADD or ADHD, but the protocol is without the use of drugs?

Ms. RICHARD. I think there are probably professionals who appear later who would be better able to respond to that. In terms of what we know about effective treatment, the use of medication shouldn't be a part of assessment, that it may be for many people, for many of our CH.A.D.D. families a part of treatment.

Mr. SHAYS. Is it always a part of treatment?

Ms. RICHARD. No; absolutely not.

Mr. SHAYS. I was just wondering in the case of some in the past, without knowing the name of the disease, a parent intuitively has discovered the treatment. Do you know what I'm basically saying? In other words, they have recognized the child has a challenge, their child, their loved child. It hasn't been diagnosed. But, intuitively, they have been able to help that child through non-chemical means.

Ms. RICHARD. I believe you're absolutely right. We absolutely do try to help our children through nonchemical means.

Mr. SHAYS. No, you're missing my point. My point is years before we put a name to this problem.

Mr. MORRIS. If I may comment?

Mr. SHAYS. My intellect tells me that there were many people—if this is a problem that has gone on for years, there were many people who were untreated who somehow survived and maybe survived quite well. And maybe they had to—you, obviously, Mr. Morris, had to compensate. You developed certain talents in your life to compensate for your—how this disease prevented you. And it made life difficult for you, but you compensated. You survived. You grew as a person in other ways.

But I'm saying something more than that. I'm saying that there may have been some parents that actually were able to treat their children much the way a doctor would treat them now, and they never knew it. They just did it intuitively or struggled with it. I mean, I may have someone tell me I'm an idiot, but that won't be the first time.

Mr. MORRIS. Let me just comment that, first of all, it's very clear that attention deficit disorder is full range. There is mild attention deficit disorder and there is very severe. We have always diagnosed attention deficit disorder, always. But it was always—before we created a mental framework for it, we diagnosed it in a moral

sense. It wasn't a problem with your brain. It was a problem with your will. Right. It was a matter of your character.

So if you're dealing with somebody who has severe attention deficit disorder, they simply got diagnosed by their peers, by their family, by their employers, simply as bad people, just as people who were just—just problems.

Now, at the other end of the spectrum, you have someone who has mild attention deficit disorder or heading up into moderate. And these people who are given tremendous structure as children, tremendous role models, tremendous support and encouragement—I dare say that if my brother in the third grade had met that one teacher that made him feel like a million bucks, that showed him the way, that perhaps he'd still be here today. Does that make sense?

Mr. SHAYS. We're on the same wavelength, yeah. I am going to conclude this panel, unless you have something else to say. You all were very valuable to this committee.

Thank you all for being here. Our last panel is Dr. Dwyer, Dr. Swanson, Denise Conrad and Dr. Zarin. If they would come to the witness table.

I might say for the record, Dr. Jensen and Dr. Danielson and Dr. Schiller, it's nice that you have remained. Sometimes when we have our first panel they have left by now. Now, I don't want to say that because you were just planning to leave. But I will note for the record that our first panel has stayed. And that's appreciated, because that way we might be able to have a continued dialog. Thank you.

I'm sorry. If you would stand, I'd like to swear you in.

[Witnesses sworn.]

Mr. SHAYS. For the record, note that all of our witnesses have responded in the affirmative. If you remembered the way I called your names, we'll start that way. We'll start with Dr. Dwyer.

STATEMENTS OF KEVIN DWYER, ASSISTANT EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS; JAMES SWANSON, PSYCHOLOGIST, DEPARTMENT OF PEDIATRICS, UNIVERSITY OF CALIFORNIA, IRVINE; DENISE CONRAD, CLASSROOM BEHAVIOR MANAGEMENT SPECIALIST FOR THE TOLEDO, OH, SCHOOL SYSTEM; AND DEBORAH ZARIN, REPRESENTING THE AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY AND THE AMERICAN PSYCHIATRIC ASSOCIATION

Mr. DWYER. Thank you, Mr. Chairman. First of all I need to be called Mr. Dwyer, because I'm not a doctor.

Mr. SHAYS. I'm happy you said that. I always want to make sure if you are a doctor, we call you that. But you're still an expert in the eyes of this committee.

Mr. DWYER. Thank you very much. My name is Kevin Dwyer and I'm the assistant executive director for the National Association of School Psychologists. Our mission as school psychologists is to protect the rights, welfare and education and mental health of all children and youth. NASP represents over 19,000 school psychologists and related professionals across the Nation.

In addition to my role as NASP representative, I have worked in the schools for more than 31 years. And I've served about 8,000 kids during that period of time and enjoyed every minute of it, by the way.

I am also the parent of a child with attention deficit hyperactivity disorder, who is now an adult and who was on medication. And he's one of my seven kids. So I have a large sample to check with him with, to see how he is different from some of the others. I have experienced both in the role as a professional and as a parent in dealing with attention problems and impulsivity.

When we're thinking about attention deficit disorder, we must remember that we're talking about people, we're talking about children. We're talking primarily about people who are going through life sometimes, if undiagnosed, feeling that they are dumb, strange, bad. They get frustrated very easily. They're confused. They're puzzled. And when they can't learn and when they don't have friends, they really feel pretty alone and pretty upset.

As a parent of a child with ADHD, I noticed that there was something wrong with my son when he was 2. And he was diagnosed at that time. And, again, in those days, he was diagnosed with minimal brain dysfunction, the term used for ADHD.

Mr. SHAYS. I don't want to interrupt you. I know I had that in my statement. What did that mean to you at the time?

Mr. DWYER. Well, as a school psychologist even at the time, it meant that I was worried that he would have learning disabilities and that he would continue to——

Mr. SHAYS. But what was the general concept of what that term meant?

Mr. DWYER. That there was something neurologically wrong with my son, and that that neurological problem was manifested in his inability to sustain the kind of attention that was necessary to even watch a ball roll across the floor at the age of 2 when, you know, I always did that with my kids.

Mr. SHAYS. So it had basically the same concept that we are trying to describe today.

Mr. DWYER. Exactly. It's just that in those days when I took him to a neurologist, it was that that disability or disorder was not really recognized at the time.

Children in the United States are diagnosed with this disorder at about 4 to 5 percent of the national population. And that's a much higher rate than any other country. And I think Dr. Swanson will probably want to talk about those things. And I want to make sure that I don't overlap too much with his work.

But in recent years, we have also become aware of the relatively safe medication, Ritalin, being abused as a drug. There is some concern about that. So it is a safe medication, but it's being abused—not necessarily by the people who it gets prescribed to, but by others particularly in middle and high schools. This is an occurrence that's just occurred in the last couple of years.

School psychologists are very concerned about the overidentification or the misidentification of children with ADHD, because it's been on such a dramatic increase. And some believe, actually, that one of the reasons it's on an increase is because there is a treatment. In other words, in this country, for example, under special

education, we don't call many children seriously emotionally disturbed because there aren't good programs for the children. But if you have something that looks like it's going to really work effectively with kids, it might be more likely for a person to diagnose a child ADHD because there is a treatment, the treatment being Ritalin.

But some also believe that our environment is changing dramatically, and the environment is much more overstimulating than it was when you or I grew up in the sense that there is too much stimulation for kids and that some of this overstimulation is reenforcing what might be called impulsivity. And I want to focus on impulsivity more than attention.

You know the ad that says, just do it. It's not exactly helping kids learn reflective thinking. There are many movies and shows that portray quite impulsive and sometimes even violent means for problem solving. And, hopefully, we're going to deal with that in our society.

Nearly 75 percent of children today are latchkey children. It doesn't mean that they're all from single-parent families, but rather both parents are working. So they come home after school, to a house where there is no adult supervision. During that period of time when they're home, the Center for Disease Control and Prevention says an awful lot of things happen that are called risky behaviors. Children are not learning the kind of control that they need to learn. And they're being given responsibility before they're able to handle it. And that's something that we need to think about.

The other thing is, too, high schools. It's wonderful that they're moving to higher standards in this country and higher requirements for graduation rates. But these are the demands that are being placed on young adults that weren't placed on the 1950 population. To get a high school diploma in 1950, quite frankly, it was easier. You didn't have to take a language or algebra to get a diploma. And the job market was very different in those days, too. And the type of job market we're dealing with is much more complex.

In our recognition of the complexity of diagnosis, we believe that a diagnosis cannot be done unless it's comprehensive. In other words, we cannot rely on these quick 15-minute doctor-office visits to make determinations that a child has ADHD. We must, as a Nation, look for best practices in diagnosis.

And diagnosis involves making sure that we do rule out other serious disorders, like anxiety disorders, and like even, believe it or not, child abuse situations which could cause young children also appear to be inattentive and to be impulsive. Conduct disorders, obsessive compulsive disorders, depression and other disorders that have been mentioned before.

It is imperative that in that process of diagnosing, we look at children in their natural environments. And as Dr. Jensen was talking about, it is not just a test that we need. And, by the way, there is no test. There is absolutely no test for ADHD. That's very important for people to realize, particularly parents. And it is important that when we look at the children in the environment, that we try things with those children to see if we can modify that envi-

ronment to see if we can get, if you wish, their impulsivity or their attention under control prior to diagnosing ADHD and putting them on medication.

In other words, we modify the environment first, before medicating these youngsters.

The other thing that we need to do—and I think if we're going to talk about doing research, one of the things we need to do is we need to find out, if you have a class of 35 kids and no supports in the school and the community has a lot of stress, and you're coming from a single parent family, is that what's causing the problem? Rather than the fact that you have a neurobiological disorder. In other words, shouldn't we start comparing environments to each other to see whether those environments end up having higher incidents of referrals for this disorder versus another environment?

We know, for example, that when you get into schools that really do comprehensive systematic efforts to help children learn skills, social skills, to help children learn to be reflective, to help children stop and think before they respond, we know that these schools have many fewer referrals. We know that these schools don't have 5 or 6 percent of their kids on Ritalin.

So there is something—they're telling us something there and this is something that we need to do more research in. It's not just—as one of my colleagues will tell you, I think there are about 9,000 research studies that have been done on medication for attention deficit disorder. There haven't been 9,000 studies done on classroom and behavioral management interventions. And especially the kind that would be longitudinal to see the impact they have on graduation rates. We need to do more of that.

And that's something I would like to see get some support both from the Department of Education, more support from the Department of Education and from our leaders like yourselves.

Some of the other recommendations I'd like to make—and the rest of my testimony you have—is that I would like to see programs that help teachers, parents and mental health providers understand the normal range of behavioral temperament. That kids do—you know, kids are different. Every one of my kids—I have seven—every one of them is different from the other one. None of them behave in exactly the same way. But the one who has this disorder was clearly and distinctly different.

The other is to ensure that all children who have and who are suspected of this disability are really diagnosed accurately and effectively. And if teachers and parents are given information and understand how to deal with normal behavioral disruptions, parents—you don't have to get a license to be a parent. You don't have to take any course to become a parent. And, frankly, our families are spreading much further apart today, so parents need some help and support in learning effective ways to keep kids' attention and to help kids behave.

When evaluating children with ADHD, we must use a multi-disciplinary approach and we must include those observations and interventions. Kids who do get this kind—who do have this diagnosis and even kids with problems, particularly mental health problems, should have a comprehensive plan, a comprehensive treatment plan, not just a pill, a comprehensive plan. It's very im-

portant. And they need to learn as Mr. Morris said. They need to incorporate some of those skills into their own behavior, so that they can do things, they can carry those things into adulthood.

We must look at classrooms that really do work and we also must think about interagency, the collaboration between agencies to be more effective.

I'm sorry I took so long. Thank you.

[The prepared statement of Mr. Dwyer follows:]

Dear Chairman Shays and Members of the Subcommittee:

I am pleased to offer my testimony before you today on the diagnosis and treatment of attention deficit disorder (ADD) and attention deficit hyperactivity disorder (ADHD) on behalf of the National Association of School Psychologists (NASP). My name is Kevin Dwyer, and I am NASP's Assistant Executive Director. Our mission is to protect the rights, welfare, education and mental health of all children and youth. NASP represents over 19,000 school psychologists and related professionals across the nation and abroad. In addition to my role as NASP representative, I have worked as a school psychologist with more than 8,000 children over 31 years and am the parent of a child with ADHD who was on medication. I have experienced both the professional and parent roles in dealing with attention problems and impulsivity. For the sake of consistency, I will use only the acronym ADHD when referring to the conditions under discussion.

When thinking about ADHD, we must remember that we are talking about individuals--primarily children. In the United States, children who are diagnosed with ADHD are very likely to be immediately placed on stimulant medication. Children in the United States are diagnosed with ADHD at a rate of about 4% to 5% and our national rate is as much as 30 times greater than in other comparable countries (Swanson, 1993). The diagnosis has increased dramatically over the past 15 years as has the use of Ritalin and other psychotropic medications (Swanson, 1996). In recent years, we have become aware that the relatively safe medication, Ritalin, is an abused drug among youth of middle and high school age (USDJ, 1995). Children with untreated ADHD frequently feel strange, bad and dumb. They get frustrated and remain confused and puzzled when they can't learn and when other children they wish to befriend shun them.

School psychologists are very concerned about the increase in the number of children being identified as having attention deficit disorder, particularly those with troubling impulse problems. Why are there so many children being labeled with this "neuropsychological syndrome"? Some believe that the answer is that the diagnosis is made because there is a quick, easy prescriptive treatment - a family of medications which includes Ritalin. Some also believe that today's child is being overstimulated to act on impulse. The ad on television says, "Just do it!" and many movies and shows portray quick, impulsive, sometimes violent means to problem solving. Nearly 75% of children are "latch-key" children, returning from school to homes where there is no adult supervision (Spillane, 1996, June). What types of impulse control and study skills are these children learning?

NASP, recognizing this rapid growth in the labeling of children with the ADHD diagnosis developed a position statement designed to carefully address this complex issue (See Appendix). NASP recognizes the condition in the context of individual differences in temperament and the numerous causes for such patterns of behavior. NASP supports the use of classroom and home interventions, careful and comprehensive diagnosis, as well as support and training for educators and parents. NASP believes in addressing the academic and behavioral needs of the children, and recognizes the use of medication as part of the menu of interventions.

Diagnosis is Complex:

The diagnosis of ADHD is very complex. Children with attention, impulse and inhibition control problems do have visible difficulties which separate them from their normal, easier to teach and to parent, agemates. Some, but not all, are academically and socially unsuccessful. Frequently, they seem unable to sustain the effort necessary to complete school work. They don't respond positively to the regular classroom management techniques teachers have been trained to use. They sometimes seem less cooperative and more self-centered in social situations, making it hard for them to keep friends or play team sports. These difficulties or symptoms are sometimes internal to the child but can also be normal coping strategies to frustrating and hostile environments. For example, an abused child may show inattention. These symptoms can also be signs of another problem. A child who has some learning difficulties and is confused by poor instructional techniques can learn to survive by tuning out or by appearing to "act out." Even gifted children can appear inattentive when bored. Cultural and experiential differences children bring to school can make the adjustment to classroom expectations difficult. Children with depression and anxiety disorders may also show the same symptoms. Children with obsessive compulsive and conduct disorder may also be diagnosed ADHD (Morriss, R., 1996). More comprehensive evaluations may uncover other conditions which initially appeared to be ADHD.

Complicating matters further is that some of these children, even those under environmental stress, may respond to the same medication that works for children with ADHD. However, in these cases the medication masks the real problems--which may fester and worsen if left undiagnosed and untreated. Accurate diagnosis is critical. Early diagnosis is important. Yet, in some situations, today's primary care physician may be forced to make this diagnosis under a 15-minute guideline from a managed health care company.

Unlike screenings for tuberculosis, vision or hearing disabilities, ADHD has no one test or set of tests which affirm the diagnosis. Even the best rating scales don't tell us everything about the child's environment. Checklists can be completed in a biased self-fulfilling manner. Conclusive results are difficult to obtain given limited input, and may result in inappropriate diagnosis and treatment. Therefore, children who appear to have attention and impulse problems need a thorough evaluation which includes instructional and behavioral intervention. The proper diagnostic process also must include observations by qualified professionals in several settings. The process must include an adequate history of the child's development and experiences, as well as the investigation of factors which can produce patterns of inattention. It is also important to have a clear understanding of the child's learning skills and cognitive abilities. The child with learning disabilities, the slow learner and the gifted may all be appear inattentive.

High Incidence:

There is a need for research into the rate of diagnosis and level of use of medication, particularly in environments where class size is large or teachers are poorly trained to accommodate for normal temperamental and cultural differences as compared to environments where class size is reasonable and teachers and parents are trained to help children learn the skills of reflective thinking and impulse control. We need to look at the availability of pupil service providers (such as school psychologist, school social workers and school counselors) and other factors which may influence frequency of referral and incidence levels. It is also believed by some practitioners that interagency collaboration in the diagnosis and intervention plan for referred children can produce better, more accurate results.

Medication versus Comprehensive Intervention Plans:

According to Dr. James Swanson of the University of California, Irvine, in testimony to the Institute of Medicine last week, there are over 9,000 research articles on medication for ADHD. But we have only a few research studies on the effects of teacher training in classroom control, behavior management, social skills training or cognitive impulse control. Many of these interventions are low in cost and relatively easy to incorporate into the regular classroom. A simple daily report to the child and parents regarding feedback on four or five behaviors can help, for example: Getting started, staying on task, completing work and being ready for change. If you teach the child what to do and give her/him very frequent reminders (with parents providing reinforcement) and change will result. Classroom accommodations for children with attention difficulties have been reported to increase measured student success in sustained productivity. Simply helping children recognize through intermittent reinforcements that they are accurately completing academic tasks increases learning. Having students work in small, cooperative learning situations increases attention and interest. Some children respond to self monitoring systems that they can have validated. Others need a response/cost system where they lose valuable reinforcements if they engage in impulsive behaviors which substantially disrupt the classroom.

Even in high school, teachers who provide detailed outlines and assignment reminders are likely to be more successful with ADHD students. Several school psychologists have trained middle and high school teachers to "coach" youth with ADHD for 10 to 15 minutes a day. The coach helps the ADHD youths to verbalize their plans to complete assignments or study tasks in order to reach a self developed long-term goal. Whatever was agreed to is evaluated for follow through. Under these circumstances, youth with C/D grade averages have moved to A/B grade averages in college preparatory courses.

School Wide Programs:

We have some field-based research and demonstrations of effective school-wide programs and the results would suggest that children in such schools are likely to show reduced patterns of disruptive behavior; greater time-on-task; less use of medication and; fewer referrals for special education.

For instance, Project ACHIEVE, a school-wide program implemented in selected counties in Florida, Alabama and elsewhere, has shown disruptive behaviors and discipline referrals decreased by up to 88% (NASP, 1995). This program helps teach children to "stop-and-think" and allows schools to use their professional resources to provide teacher and parent consultations in order to have fewer classroom disruptions and more time-on-task.

Conclusion:

Medication alone cannot address the needs of children with ADHD. There must be a planned effort to analyze each individual's specific blocks learning and behaving appropriately. The child needs to learn strategies that will result in success. The child's teachers must be trained to accommodate and reinforce those strategies. Parents need help in being consistent, in sustaining and refining their skills and in supporting what the school is doing. Behavior management strategies are important but it is also critical to be "strength focused," giving these children the praise and positive attention they need. Children with identified ADHD experience more frustration than their normal peers. Over their childhood they may find themselves being "treated" by many systems, none of which is aware of what the other is or has tried. This only increases frustration.

Communities must come together to help these children and other children with emotional and behavioral problems to succeed. The schools can play an important role but others must assist in the reframing of how we look at these children. Presently we know that too many of these children fail in school, in the work place and in the community. We know many things that appear to have merit. We need to support those efforts and evaluate them more carefully over time.

Recommendations:

1. Help all teachers, parents, health and mental health providers to understand that the range of normal behavior in children is far greater than is commonly acknowledged.

2. Ensure that every child who is suspected of having ADHD is accurately diagnosed.

3. Provide teachers and parents with information and, when appropriate, training to

address normal problems of inattention, and lack of sustained effort and productivity.

4. When evaluating a child for ADHD, one must insist upon a multi-disciplinary approach which includes observations of the child by qualified professionals in more than one setting and an evaluation which rules out other mental and social conditions. Avoid the 15 minute diagnosis - prescription approach.

5. If children are found to be ADHD and in need of medication, ensure that they receive a comprehensive treatment plan which includes teacher training, parent support, and specialized training for the child which has the potential to be generalizable and long-lasting.

6. Examine classroom, school and community factors which can reduce the negative impact of ADHD and support those factors.

7. Support community-based interagency and interprofessional service solutions and enable communities to access multiple resources and funding streams to help prepare children for school and schools for children. Early diagnosis and intervention which includes parent support and skill building can reduce later more costly interventions.

8. School reform efforts at the local and state levels should consider the importance of teaching children thinking, learning and social skills. These are the skills needed to be successful in school and the workplace, and help reduce adolescent high risk behaviors which result in violence, teen pregnancy, drug abuse and failure.

9. ADHD can have a life-long impact and the transition from high school to college, training or work will be more successful when the problem is addressed in those environments. Personal advocacy and compensatory skills are critical for adults with this condition.

10. By the year 2000, all schools should have problem solving teams in place which help teachers and families through consultation and support to address the problems related to ADHD and other psychosocial and cognitive blocks to learning. These teams should include individuals with the knowledge and understanding of the diagnosis and treatment of ADHD, such as school psychologists.

Thank you for this opportunity to present NASP's views before the Subcommittee. I would be happy to answer any questions you might have at this time or in the future.

References

Fiore, T. (1994). Education interventions for students with attention deficit disorder. In Executive summary of research syntheses and promising practices on the education of children with attention deficit disorder, Washington, DC: Chesapeake Institute.

Morriss, R. (1996). Conditions that mimic ADD: Explaining the epidemic of attention deficit disorders. Carmel Valley, CA: Village Press.

NASP. (1995). School psychologists: Helping educate all children. Bethesda, MD: Author.

Spillane, A. (1996, June). School violence. Presented at a briefing, National Press Club, Washington, DC.

Swanson, J.M. (1996, July). Prevalence of office visits for ADD: Gender differences between 1990-1994. Presented at the planning meeting on ADHD: Issues of Definition, Diagnosis, and Management. Institute of Medicine, Washington, DC.

Swanson, J.M. (1993). Effect of stimulant medication on children with attention deficit disorder: A review of reviewers. Exceptional children. 60, 154-162.

U.S. Department of Justice, Drug Enforcement Administration. (October, 1995). Methylphenidate: A background paper. Washington, DC: Author.

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

4340 East West Highway
Suite 402
Bethesda, MD 20814

301-657-0270
FAX: 301-657-0275
TDD: 301-657-4155
E-mail: SPB455@AOL.COM

Position Statement

Students With Attention Deficits

The National Association of School Psychologists advocates appropriate educational and mental health services for all children and youth. NASP further advocates noncategorical models of service delivery within the least restrictive environment for students with disabilities and students at risk for school failure.

NASP recognizes that there are students in schools with academic and adjustment problems who exhibit a constellation of behaviors commonly associated with ADD/ADHD (Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder). NASP also recognizes that it is difficult to distinguish attention deficits so severe as to require special education from the normal range of temperament and fluctuations in attention to which all students are susceptible.

Longitudinal data suggest that the problems associated with attention deficits present at an early age, may change over time, and that they may persist into adulthood. Therefore, NASP believes that interventions must be designed within a developmental framework. Furthermore, recognizing that these students are at particular risk for developing social-emotional and learning difficulties, NASP believes problems should be addressed early to reduce the need for long-term special education.

NASP believes that students with attention deficits can be provided special education services as appropriate under disability categories currently existing in EHA/IDEA. While concern has been expressed that children with attention deficits served in existing categories will not receive the most appropriate instruction for their unique needs, research indicates that disability categories or areas of teacher certification have no significant effect on instructional methods or on effectiveness of service.

NASP believes that excessive emphasis on assessment and diagnosis at the expense of developing and monitoring effective interventions is not in the best interests of children. Assessment of youngsters with possible attention deficits should include intervention assistance to students and their teachers as pre-requisites to a formal assessment process.

NASP believes that effective interventions should be tailored to the unique learning strengths and needs of every student. For children with attention deficits, such interventions will often include the following:

1) Classroom modifications to enhance attending, work production, and social adjustment;

2) Behavior management systems to reduce problems in areas most likely to be affected by attention deficits (e.g., unstructured situations, large group instruction, transitions, etc.);

3) Direct instruction in study strategies and social skills, within the classroom setting whenever possible to increase generalization;

4) Consultation with families to assist in behavior management in the home setting and to facilitate home-school cooperation and collaboration;

5) Monitoring by a case manager to ensure effective implementation of interventions, to provide adequate support for those interventions, and to assess programs in meeting behavioral and academic goals;

6) Education of school staff in characteristics and management of attention deficits to enhance appropriate instructional modifications and behavior management;

7) Access to special education services when attention deficits significantly impact school performance;

8) Working collaboratively with community agencies providing medical and related services to students and their families.

NASP believes appropriate treatment may or may not include medical intervention. When medication is considered, NASP strongly recommends:

1) That instructional and behavioral interventions be implemented before medication trials are begun;

2) That behavioral data be collected before and during medication trials to assess baseline conditions and the efficacy of medication; and

3) That communication between school, home, and medical personnel emphasize mutual problem solving and cooperation.

NASP believes school psychologists have a vital role to play in developing, implementing, and monitoring effective interventions with students with attention deficits. As an association, NASP is committed to publishing current research on attention deficits and to providing continuing professional development opportunities to enhance the skills of school psychologists to meet the diverse needs of students with attention deficits.

Adopted NASP Delegate Assembly
September 1991

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

Attention Deficit Disorder

A Primer for Parents

November 1995

by Elaine Morton Bohlmeyer, Ph.D, NCSP, with the school psychology staff of Gilbert (AZ) Unified School District

When a student is not doing well in school, especially if teachers also report that the student doesn't seem to concentrate in class and does not complete or turn in work, the parents may wonder if the child has an Attention Deficit Disorder (ADD). Sometimes such children are labeled "hyperactive," although it now is recognized that children can have attention deficits with or *without* overactive behaviors. It is important for parents to recognize the symptoms of ADD and to work with professionals in making an accurate diagnosis.

Characteristics of ADD

Students who have ADD may display a variety of characteristics, but some of the most common are impulsiveness, inattention, disorganization and distractibility. These children are often described as:

- not thinking before they act
- having difficulty following complex directions
- unable to wait
- having difficulty maintaining attention to tasks that are not basically interesting, such as school work or chores (but they may be able to watch TV or play computer games for hours!)
- unable to comply with a schedule
- frequently losing things.

Parents often will say, "Even when I see him complete his homework, it never seems to get turned in." It is as if a "black hole" follows some of these children and swallows their homework and supplies. Some children get into fights often and are avoided or rejected by their peers. Others are very likeable and have many friends, although their friendships usually are not deep and lasting. They may get into trouble in school and in the community for doing things they know they shouldn't do, and they may be either extremely sorry or have a great many reasons why it wasn't their fault. The child may relate a feeling of being out of control or not being able to stop an activity. Parents may ask, "I know he knows better, and I know he's a good kid; why is he always in trouble?"

Diagnosing ADD

Many of the symptoms associated with ADD also may be symptoms of other childhood problems such as depression, anxiety or conduct disorders. Another problem with diagnosis is that there is no blood test or other specific medical test for ADD. Physicians and psychologists who diagnose ADD use observation, behavior reports form people who know the child well and a careful history. Sometimes there is a family history of ADD. In addition, the child's personal history is important because symptoms of true ADD will be present in a child before age seven and will be persistent over the years. If a child suddenly begins to exhibit these symptoms, especially if the child is older than seven, the behavior usually is a temporary response to something that is troubling him or her; however, it also may be the beginning of a deeper emotional problem.

Helping Children with ADD

Treatment of ADD is most successful when a variety of approaches are taken. First, it is important for parents to obtain as much information as possible about ADD. They can attend support groups in their school or

community and there may be lectures and seminars provided by their school or mental health agencies. It helps for parents to meet together to learn that they are not alone with this problem and to discuss what other parents have found helpful. The school psychologist should be able to provide information about various resources and reading material.

Second, it usually is helpful for the child to have some individual or group counseling. Counseling may include information about ADD, social skills training and techniques that help the child remember to focus and think before acting. Older children may be taught strategies that will help them organize and complete tasks, such as using notebooks, checklists or timers.

Third, behavior techniques used by parents and teachers can help the child be more successful in meeting the demands of tasks. Since most ADD children really do want to behave well and to be able to finish assignments, they may respond to a prearranged nonverbal signal to return to their work. Positive reinforcement (praise, rewards) for following instructions and completing work may be helpful, but such reinforcement needs to be immediate and frequent. Children with ADD do not respond well to long-term rewards; opportunities to earn rewards need to be given every few minutes for preschoolers, several times a day for young elementary school children and at least daily for adolescents. Other specific techniques include:

- give the child only one or two steps of a direction at a time
- break a school assignment into several short assignments that an adult checks after each part is completed
- set a timer for a short period of time and challenge the child to see how much of a task can be completed before the timer goes off
- help the child to keep a daily calendar
- help the child to organize homework into a notebook.

Using Medication for ADD

Finally, a physician might choose to prescribe medication. ADD is a neurobiological condition and medication helps the child to focus and benefit from instructional and behavioral support. Although some parents are reluctant to give their children medication, research shows that other treatments without the medication component rarely have lasting effects.

A great deal has been learned about ADD during the past five or ten years, so it is important to know what information is current and what is outdated. For example, professionals used to believe that children "outgrow" ADD at puberty and that medication and other treatments were not needed after that time. It now is know that, while most children do outgrow the excessive motor activity often associated with ADD, many people retain other symptoms throughout their adult lives and continue to respond favorably to counseling and medication. There is also evidence that some popular treatments, such as biofeedback, special diets and herbs, are ineffective. Until recently, it was thought that medications used for ADD might permanently stunt children's growth or worsen symptoms of Tourette's Syndrome (such as tics), but new information does not support these fears.

What if I suspect my child has ADD?

If you suspect your child has ADD, you can expect the school to help you by providing behavior reports from teachers, either in written summaries or in the form of structured questionnaires or rating scales. If you have concerns about your child's academic progress or behavior, the school also should investigate whether or not symptoms of learning disabilities or emotional disorder are present. If your child is diagnosed as having ADD, the school is obligated to make reasonable accommodations for the child's condition, such as preferential seating or giving the child more time to complete assignments.

To pursue medical treatment, be sure to see a physician who is knowledgeable about ADD and medications. Work with your physician to find the right medication and the right dosage for your child. It used to be thought that dosage should be dependent upon body weight, but now it is known that each child responds differently to dosage level. During the time of adjustment, remember that most medications prescribed for ADD are short-acting and any undesirable (as well as favorable) effects wear off quickly. That is why many of these medications must be taken every few hours. If, however, your child also is being treated for other conditions, such as depression, the effects of medication for these other conditions may be longer-acting. Be sure to discuss side effects with your physician and report any concerns immediately!

Expect the school and physician to work together and communicate regarding the effectiveness of behavior techniques and response to medications. Both educational and medical professionals have unique contributions to make in the treatment process. While reports from school are crucial for monitoring the effects of medications, nobody in the school setting is qualifled to prescribe them or change the dosage. While the physician may give helpful educational recommendations, it is not within the authority of a physician to prescribe specific tests or treatments within the school setting.

If your child is diagnosed as having ADD, remember that this condition likely can be fairly well controlled, but it also probably will be a life-long condition. Despite the best treatment, your child may never be as organized and methodical as typical peers. For example, do no expect your child to remember to take medication according to the prescribed schedule unless he or she clearly has demonstrated the ability to do so. Remember that, when your child needs the next dosage of medication, the effects of the last dosage are wearing off and that this is when the child tends to be least well-organized and responsible. Your child may always need more that the usual amount of help to organize tasks and materials, and he or she may never conform to rules and regulations as closely as you would like. However, if you emphasize the child's unique strengths and abilities, the disability may not seem so frustrating.

Resources for parents

CHALLENGE Newsletter, Challenge, Inc., P.O Box 488, W. Newbury, MA 01985; $25/yr. A national newsletter on Attention Deficit Disorder published six times a year.

Garber, S. W., Garber, M. D., & Spizman, R. F. (1993). *If Your Child is Hyperactive, Inattentive, Impulsive, Distractible...* New York: Villard Books.

Goldstein, S. & Goldstein, M. (1992). *Hyperactivity: Why Won't My Child Pay Attention?* New York: John Wiley & Sons, Inc.

Goldstein, S. & Goldstein, M. (1995). *A Parent's Guide: Attention-Deficit Hyperactivity Disorder in Children.* Salt Lake City, Utah: The Neurology, Learning & Behavior Center.

Ingersoll, B. D. & Goldstein, S. (1993). *Attention Deficit Disorder and Learning Disabilities: Realities, Myths and Controversial Treatments.* New York: Doubleday.

Maxey, D. W. (1993). *How to Own and Operate an Attention Deficit Kid.* Roanoke, VA: CHADD Support Groups.

Moss, R. A. with Dunlap, H. H. (1990). *Why Johnny Can't Concentrate.* New York: Bantam Books.

Silver, L. B. (1993). *Dr. Larry Silver's Advice to Parents on Attention-Deficit Hyperactivity Disorder.* Washington, DC: American Psychiatric Press, Inc.

Organizations

ADDAPPT: Attention Disorders Association of Parents and Professionals Together. P.O. Box 293, Oak Forest, Il 60452 (Publishes ADDaptibility Newsletter)

C.H.A.D.D. (Children and Adults with Attention Deficit Disorders). 499 NW 70th Av #109, Plantation FL 33317. (305) 587-3700.

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

Helping Students with Attention Problems:

Strategies for Teachers

November 1995

by Marcia Weill
Folsum-Cordova (CA)Unified School District

Hyperactivity: Provide External Structure

Physical Controls
- Give energy breaks, opportunities for focused movement
- Provide individual desks & space for extra materials
- Include short, fast-paced tasks
- Be calm (soothing music, carpet, earplugs)
- Develop physical cues to refocus

Predictability
- Minimize changes and pullouts
- Prepare for transitions
- Practice routines

Distractibility: Focus on Priorities

Priorities
- Use anticipatory set with frequent restatement of purpose
- Provide only needed materials
- Modify tasks: shorten, highlight, use markers and windows for tracking, break into manageable steps
- Teach summarizing skills — one idea per paragraph or page

Directions
- Start with one step, student restates in own words before performing independently
- Vary voice pitch and pacing of lesson
- Teach memory strategies (mnemonics, note taking, brain storming)
- Insist on instructional readiness (body still, eye contact)

Distractors
- Use multi-sensory materials and "hands on" learning to engage
- Locate student away from visual and auditory distractors (heating/air conditioning, traffic and stimulating bulletin boards)
- Seat student by organized, understanding peers

Impulsivity: Build Self Confidence

Social Skills
- Give opportunities for leadership, being a tutor for younger students, reinforce each step to success
- Use cooperative learning groups, giving a responsibility he or she can do
- Provide practice making choices, impulse control, empathy

Parent Support
- Send frequent progress reports
- Give honest feedback, mostly positive

Counseling
- Reinforce time-on-task (process), fading to task completion (product)
- Encourage risk-taking and positive self-talk
- Build on strengths, teach compensating skills and remind of successful accomplishments
- Use contracts with frequent reinforcement for desired behaviors and response-cost for negative behaviors

...ted from material previously published by the California Association of School Psychologists in CASP Today, *August 1994.*

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

Helping Children with Attention Problems:

Strategies for Parents

November 1995

By Marcia Weill,
Folsum-Cordova (CA) Unified School District

Hyperactivity: Provide External Structure

Physical Controls
- Include regular exercise, balanced diet, adequate sleep, medication if appropriate
- Check schedules: mornings usually best for learning, need calm routine at bedtime
- Check environment for safety and remove treasured items, prevent problems

Predictability
- Use consistent rules across time and place
- Prepare for changes to new activity
- Practice simple daily routines
- Have regular contact with school

Distractibility: Focus on Priorities

Priorities
- Organize backpack and notebook
- Have a "Launch Pad" area for next morning's materials and messages
- Encourage on-task behavior
- Request special education assessment if appropriate

Directions
- Use simple, positive directions showing what to do instead of what not to do
- Give visual clues

Distractors
- Provide regular time and clean area for doing homework
- Limit and balance extracurricular activities

Impulsivity: Build Self-Confidence

Social Skills
- Build on strengths
- Teach game-playing skills, taking turns and making choices
- Encourage noncompetitive sports (karate, gymnastics, swimming)
- Teach friendship skills (making requests, giving compliments, less rough play)

Parent Support
- Enroll in classes in behavior management
- Join support groups
- Use "special time" for bonding

Counseling and management
- Use strategies to reduce impulsive behavior
- Model positive self-talk and goal-setting
- Reward frequently

Adapted from material previously published by the California Association of School Psychologists in CASP Today, *August, 1994.*

NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

ADD: Resources for Parents and Educators

November 1995

Books

Barkley, R. (1990). *Attention Deficit Hyperactivity Disorder: A handbook for diagnosis and treatment.* New York: The Guilford Press.

Cordoni, B. (1987). *Living with a Learning Disability.* Carbondale, IL: Southern Illinois University Press.

Faber, A. & Mazlish, E. (1980). *How to talk so kids will learn and listen so kids will talk.* New York: Rawson, Wade Publishers.

Fowler, M. (1992) *C.H.A.D.D. Educators Manual.* Plantation, FL: C.H.A.D.D.

Goldstein, S. & Goldstein, M. (1995). *A parent's guide: Attention-Deficit Hyperactivity Disorder in children.* Salt Lake City, UT: The Neurology, Learning & Behavior Center.

Hallowell, E. & Ratey, J. (1994). *Driven to distraction.* New York: Pantheon Books

Hallowell, E. & Ratey, J. (1995). *Answers to distraction.* New York: Pantheon Books

Ingersoll, B. D. & Goldstein, S. (1993). *Attention Deficit Disorder and Learning Disabilities: Realities, myths and controversial treatments.* New York: Doubleday.

Kelly, K. & Ramundo, P. (1994). *You mean I'm not lazy, stupid, or crazy?! A self-help book for adults with Attention Deficit Disorders.* New York: Simon & Schuster (Audiotape version also available)

Kendall, P. (1988) *Stop and think.* Merion Station, PA: Temple University Press.

Nadeau, K., (Ed.). (1995). *A comprehensive guide to Attention Deficit Disorders in adults.* New York: Brunner/Mazel

Nelsen, J. (1987) *Positive discipline.* New York: Ballantine Books.

Parker, H. (1988) *The ADD hyperactivity workbook.* Plantation, FL: Impact Publications.

Parker, H. (1992). *The ADD hyperactivity handbook for schools.* Plantation, FL: Impact Publications.

Phelan, T. (1984) *1-2-3 Magic!* Child Management.

Silver, L. (1992). *The misunderstood child: A guide for parents of children with Learning Disabilities.* Bradenton, FL: Human Resources Institute

Solden, S. (1995). *Women with Attention Deficit Disorder: Embracing disorganization at home and in the workplace.* (Scheduled for release week of October 2, 1995- call 313-663-0912 for information.)

Taylor, J. (1993). *The Attention Deficit/Hyperactive student at school: A survival guide for teachers and counselors.* Salem, OR: Sun Media.

Taylor, J. (1993). *Motivating the uncooperative student.* Salem OR: Sun Media.

Taylor, J. (1993). *Anger control training for children and teens.* Westminister, PA: Mar*Co Products.

Vernon, A. (1989) *Thinking, feeling, behaving.* Champaign, IL: Research Press.

Videotapes

Amen, Daniel. *Windows into The A.D.D. Mind.* The Center for Effective Living, 2220 Boynton Ave, Suite C, Fairfield, CA 94533 (800-793-9249)

Barkley, R. *ADHD—What Do We Know?* Guilford Press.

Barkley, R. *ADHD—What Can We Do?* Guilford Press.

Barkley, R. *ADHD in the Classroom: Strategies for Teachers.* Guilford Press.

Barkley, R. *ADHD in Adults.* Guilford Press.

Breggin, P. & Valentine, M. *The Myths of ADHD.* Children First, 23565 Via Paloma, Coto de Caza, CA 92679.

Taylor, J. *Answers to A.D.D.: The School Success Tool Kit.* Sun Media , 1095 25th St. SE, Suite 107, Salem, OR 97301; 1-800-847-1233 (available in both English and Spanish)

Compiled by Elizabeth Bohlmeyer (Gilbert AZ USD), Deborah Cross (Los Angeles USD), Michael Valentine (Coto de Caza, CA), Marcia Weill (Folsum, CA USD), and Michael Wilson (Minneapolis Schools)

Mr. SHAYS. Thank you very much. No. Ten minutes is fine. Thank you, sir. Dr. Swanson.

Mr. SWANSON. I want to thank you for inviting me to testify before your subcommittee. My name is James Swanson. I'm a professor of pediatrics and psychiatry at the University of California, Irvine. I'm a psychologist, not a physician, but I have worked with attention deficit disorder in medical school settings since the late 1970's. And since 1983, I've directed a school—a public school, actually, on the university campus that focuses on intervention, school-based interventions for children with ADHD.

In your letter, you asked me to address three issues. Why there's been an increase in the diagnosis of ADHD; how this disorder should be diagnosed; and proper treatment. And I will try to address those three.

Certainly, there has been a dramatic increase in the recognition of this disorder. And in a recent letter to the editor of the New England Journal of Medicine, my colleagues and I documented this. This was after an extensive discussion with both Peter Jensen and Ellen Schiller at the Department of Education and NIMH, because I have worked closely with them on these topics over the last several years.

We did use a commercial data base to show that there was a doubling of children, which we estimated to be about 1 million in 1990 up to about 2 million in 1994. And using census figures, Dr. Lilly Williams, who is supported by a minority supplement award from NIMH, has estimated what those prevalence figures of recognition and treatment propositions, that about 6 percent of boys and about 1.5 percent of girls in 1994 were recognized with this disorder and treated.

So, indeed, there has been an increase in the diagnosis and I posed a question in my testimony: Is this a cause for alarm? And before I answer why I think, yes, this is a cause for alarm, I'd like to tell you why I think—what things are not causes for alarm, just so I won't be misinterpreted.

I think that certainly ADHD does exist and the acceptance of it, which has been really something wonderful that parent groups have done over the last 5 years is not cause for alarm whatsoever. And I think the backlash, the question of its existence is cause for alarm, because that's not consistent with biological research that's now emerging. And I have listed several references about biological work, both in brain imaging and molecular biology, some of which my colleagues and I are doing.

And, also, I'd like to point out that the adverse consequences of untreated ADHD are clear and my colleague and I, Jim Satterfield, have published a paper in 1995 showing what some of those are, with the development of antisocial behavior that can be prevented with psychosocial treatment in combination with medication.

And, also, I don't think that the sensational claims that everyone has heard about ADHD and its treatment are really cause for alarm, because I don't think that they're accurate. These claims are, for example, about widespread abuse which I do not think is happening, or even that the drug, methylphenidate Ritalin might cause cancer. And those really are sensational claims that I don't think are accurate. And I, in my testimony, said why.

So I do think that the FDA, for example, is doing a good job of effectively balancing control of this medication, as well as access to it. So I don't think there is any cause for alarm because those people are doing a pretty good job and dealing with how we can use this medication, even though it might have potential for abuse, how we can use it to make it accessible.

But there are some reasons why I think that this increase in recognition should make us stop and pause. One is just the ever changing definition or refinement of the disorder. I think this in itself has caused controversy. Since 1980, there have been three changes in how the disorder is defined. And the most recent change is that this might be a dimension of behavior. So it's not what's called a categorical diagnosis, but it's just a variant of normal behavior and it's an extreme of a distribution. And if that's the case, then we really don't know what the prevalence is. The prevalence isn't defined. It's arbitrary.

So I think that's some cause for concern, because the way it's recognized in many settings now is by using rating scales, usually even from just a single source, perhaps the teacher. And that leads to an estimate at about 18 percent of the children have attention deficit disorder. I think that is incorrect. And as Dr. Jensen has indicated, that's not the appropriate way to diagnose the disorder. But in the literature, there are several articles saying that the prevalence is very high, 15 to 20 percent. And I think that's some cause for alarm.

I think reliance on the ratings scale has some—that has some psychometric property that are inappropriate has not been recognized. And, in fact, the cutoff score that typically is used based on statistics where a mean plus 1.65 standard deviations on a dimension is supposed to identify 5 percent of children. With this particular approach, it actually identifies about 13 percent of children.

So I think there is some over-recognition taking place because of that.

And I also think there is a cause for alarm about subthreshold problems being recognized as a disorder, again with a distribution of attention. If any cutoff point is established, there are going to be more people right below the threshold than right above the threshold. And there will be a pressure if there is a reason for this diagnosis to be made to gain benefits in some way, either in education or medical settings, for that threshold to be lowered and make the next group eligible. And I think that's some cause for alarm, because it leads to a very high prevalence rate. And I think it's a very slippery slope to start changing the cutoff value. And in some ways, we might be doing that over time.

And as most of the other people have indicated, I think the problem with no understanding the detrimental effects of a variety of adverse environments would certainly cause the symptoms, inattention, hyperactivity, and impulsivity. But it's not the disorder. And to treat those things, stress in the family due to divorce, a loss of a job by the parents, and a variety of other things, to treat that as attention deficit disorder, I think, is wrong, and that it might be a cause for alarm.

And the high false positive rates of tests that are used in some cases, I think, is also a concern. If we take a difficult school of 500

children and try to screen for attention deficit disorder and use a test that has a false positive rate of 15 percent, we'll identify 70 kids who are not ADD with the disorder, and only 20 kids who actually have ADD given that it is only represented in 5 percent of the children. That's just a fact about using a test for low base rate disorders.

The second question is, how should ADHD be diagnosed. And I think in the long run, biological tests will be used. And Dr. Jensen mentioned how these were being developed. And there is a considerable convergence on several studies using brain imaging techniques, that there are specific brain regions that are different in children, even using the messy diagnosis of ADHD that we have now. At the caudate, the right frontal lobe are smaller in these children who have the diagnosis. And also from molecular biology, we're identifying certain genes that are associated with neural transmitter system, particularly dopamine, that might result in a subsensitive neural chemical system. And this may be a reason why medications like methylphenidate, Ritalin, and amphetamines, both Dextrine and Adoral, are used, because those are the general transmitter systems that these drugs affect.

Until we have the biological tests, though, I think we should have a consensus on the prevalence and we should set that in the lower range, 3 to 5 percent, instead of the higher range as sometimes seen in the literature of 15 to 20 percent. I think we should have guidelines to constrain the use of subjective instruments like ratings scales and certainly use structured clinical interviews as Dr. Jensen described to make the diagnosis. And imposing those limiting conditions, age of onset, impairment, and manifestation across settings certainly does in some way identify the cases that truly have it.

And avoid the use of tests with even false positive rates in the order of 15 percent, because it will make more work for us to try to undo what we misidentify than actually will save us by identifying those children.

What is the proper treatment. For the Department of Education, I did a literature review. And they certainly held my feet to the fire and made me do a review. And, as Kevin said, it was 9,000 articles, all of which I couldn't read. But I certainly did review them all with a systematic methodology which Ellen Schiller imposed on me and made me learn what you call a systematic review of literature.

And what I did try to come up with was what medication does, what we should expect it to do and what it does not, what we should not expect it to do. And I don't think there is any disagreement about what a medication does and what it doesn't do. But there is still tremendous controversy about whether it should be used or not. And that's a different question than what it actually does.

And the long-term effects may require multimodality treatment, according to Satterfield's work, and only now this is being put to a rigorous test. And if this is an oversight committee for intergovernmental interactions, I can attest that the Department of Education and the National Institute of Mental Health have cooperated on a study. And it's ongoing now. It will probably be the largest

and most important study ever done on this disorder, to try and look at the long-term effects.

So, both Peter Jensen and Ellen Schiller have collaborated on the multimodality treatment study, which Dr. Jensen described. And I think this will determine whether we really, truly should emphasize more behavioral treatment to go along with pharmacological treatment so we can evaluate the long-term impact of multimodality intervention in these children.

Thank you.

[The prepared statement of Mr. Swanson follows:]

July 15, 1996

To: Christopher Shays, Subcommittee on Human Resources and Intergovernmental Relations

From: James M. Swanson, PhD, Professor of Pediatrics, University of California, Irvine

Thank you for inviting me to testify before the Subcommittee about Attention Deficit Hyperactivity Disorder (ADHD). As requested, I will give my views about (A) why there has been an increase in diagnosis of ADHD, (B) how the disorder should be diagnosed, and (C) the proper treatment ADHD.

A. Increase in diagnosis of ADHD

In a recent note to the New England Journal of Medicine (Swanson, Lerner and Williams, 1995), we documented that, indeed, a dramatic increase had occurred from 1990 to 1994 in the recognition of ADHD by physicians and prescriptions for stimulant medications to treat this condition. Also, we used census figures to estimate that by 1995 the recognition rate in school-aged children was high -- about 6% of boys and about 1.5% of girls (Williams, Swanson, and Lerner, 1995).

In this cause for alarm? I think so, but before I give reasons why, I would like to emphasize what I do not consider to cause for alarm:

- First, acceptance of ADHD as a disorder is not cause for alarm. The opposite trend (perhaps a backlash) to question the existence of ADHD seems to me to be cause for alarm, because this view is not in line with the scientific evidence – that the diagnosis is related to biological differences such as smaller brain regions (Castellanos et al, 1995 and 1996; Filipek et al, 1996) and subsensitive neurotransmitter systems related to dopamine (Cook et al, 1995; LaHoste et al, 1996), or that the diagnosis is related to serious adverse long-term outcome such as educational underachievement (Barkley et al, 1988; Gittelman et al, 1988) and juvenile arrest (Satterfield et al, 1983 and 1995). I believe that ADHD exists as a disorder, and that left untreated it is likely to result in preventable adverse consequences for the individual, the family, the school, and our country.
- Second, what appears to be greater demand than supply of clinical and educational services for children with ADHD is not cause for alarm. Anytime such a rapid increase in recognition of a disorder occurs, this type of problem should be expected and will probably be corrected by parental pressure (e.g., from CHADD and ADDA) and wise leadership in mental health and education (i.e., from NIMH and the Department of Education). The training of practitioners to make the diagnosis is lengthy, and untrained or inexperienced practitioners may introduce problems of overdiagnosis or ineffective treatment, but these problems should be corrected as training catches up with demand for services.
- Third, I do not believe that the sensational claims that a treatment for ADHD (with a Schedule II stimulant drug, methylphenidate) may cause cancer or be widely abused are not cause for concern, because these claims are not consistent with the scientific literature which

indicates that methylphenidate may protect against cancer in humans (FDA, 1995); that methylphenidate, despite an abuse potential, is rarely abused; that the recent increase is accounted for by prescriptions and not attributable to diversion for non-medical use (Swanson et al, 1995); that methylphenidate when taken orally has low bioavailablity and the talc in the tablets is insoluble, so its abuse potential is diminished (Greenhill, 1990); that methylphenidate has slow clearance from central brain sites of action which may make it an effective treatment for abuse of cocaine (Volkow et al, 1995). Thus, from a regulatory point of view about control of Schedule II drugs, the FDA seems to be doing a good job and I see no cause for alarm or reason to change an effective balance between control of abuse and access for clinical use.

However, I think more basic problems exist concerning diagnosis of ADHD, and that these problems are serious and do represent cause for alarm:

- The changing definition of ADHD is cause for alarm. Since 1980 when the current conceptualization of the disorder was proposed in the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association, the definition of ADHD has been gradually refined and modified (DSM-III, 1980; DSM-III-R, 1987; DSM-IV, 1994), but the changes have themselves created considerable controversy about the nature of the disorder and the presence or number of subtypes. Some (e.g., Ferguson and Harwood, 1995) claim that the symptoms of ADHD form a dimension of behavior, and that relative (extreme) placement on a rating on this dimension should be used to diagnose the disorder. If so, then the location of the cut-off point is arbitrary for making a "diagnosis". Since there is no definite prevalence of a "disorder", some decisions have led to very high estimates (e.g., 15% to 20%). This is a relevant question, because of the proliferation of rating scales touted for use in the assessment of ADHD. Others (e.g., Cantwell, 1994; Jensen, 1995) suggest that symptom counts (instead of a score on a dimension) should be used to make a categorical diagnosis of ADHD, utilizing age of onset, pervasiveness, and impairment along with a rating of severity to diagnose the disorder. If strictly applied, these exclusion criteria may result in a defined prevalence. However, if an arbitrary cutoff on a rating (instead of a structured clinical interview) is used to define the presence of a symptom and the DSM-IV criteria are used, then a very high prevalence estimate may still be suggested (e.g., 18% – see Baumgaertel et al, 1995)

- The reliance on rating scales from a single source to make a diagnosis is cause for alarm. Recent research suggests that when completing ratings of DSM-IV symptoms, teacher may perceive symptoms of ADHD in almost 20% of school-aged children (Baumgaertel et al, 1995; Wolraich et al, 1996). The assumption of a normal (bell-shaped) distribution of scores on a dimension (or presence of a symptom) is unlikely to be met, and if traditional statistics are used on a "J-shaped" distribution, then over recognition may be an unintended result. In the jargon of statistics, the "extreme" of a distribution may be set by assuming that a cut-off score [i.e., the mean (average) plus 1.65 standard deviations] would identify about 5% of the population as "extreme". However, we (Swanson and McCleary, 1996) have shown that for ratings of ADHD, this cut-off score actually identifies about 13% instead of 5% of an elementary school population. These properties of rating scales should be acknowledged, and

certainly this should be taken into account before recommending norms for use in diagnosis of ADHD.

- The recognition of subthreshold problems as the disorder is cause for concern. If the dimensional approach is used to estimate severity of ADHD, then at any point above the average dimensional score in the population, more individuals will have manifestation of ADHD symptoms just below threshold than just above threshold. If there are benefits from officially having a "diagnosis", this may create pressure to recognized just common problems of life as a "disorder" and to move the threshold down to label more individuals with the ADHD diagnosis. This is s "slippery slope", since at each step there will be more children with sub-threshold manifestations of ADHD whose parents may clamor for recognition and services. I believe that the current popularized version of ADHD in adults also suffer from this pressure, and has resulted in overdiagnosis of historical figures (e.g., Benjamin Franklin, Albert Einstein, Winston Churchill, etc.).
- Confusing known detrimental effects of adverse environmental with ADHD is cause for concern. I believe that certain environmental influences (i.e., poor school; stress in the family due to divorce or parent's loss of job; abuse or neglect; poverty; etc.) should be expected to increase the expression of behaviors (i.e., overactivity, inattention, and impulsivity) in some non-ADHD children who will then exceed the threshold for diagnosis of the disorder, based either on a dimensional or categorical approach. When adverse environmental factors push large numbers of individuals over the cut-off score to qualify for a diagnosis, the misidentification and treatment of these individuals for ADHD may impede or mask the need for essential environmental changes. If relative placement instead of absolute placement is used, then the prevalence at any chosen level of severity (i.e., the score that cuts-off the top 5%) should remain constant, and the focus of concern may be correctly directed toward the identification and change of adverse environments that elicit ADHD-like behaviors.
- The use of objective tests with high false positive rates to identify a low base-rate disorder (such as ADHD) is cause for concern. I believe that the use of heavily marketed versions of the Continuous Performance Test (CPT) does not solve the problem of overdiagnosis and may even make it worse. If the currently available CPTs are used to screen a population in which only 5% have ADHD, then due to the published "false positive" error rate (15%), many more incorrect identifications of non-ADHD cases will be made than correct identifications of children with ADHD. Thus, the use of some objective tests, although well-intentioned, may create more work than it saves (to undo mistakes) when used to screen for disorders with relatively low base-rates.

B. How Should ADHD Be Diagnosed?

In the long run, the use of biological tests should be used to diagnose a disorder with a presumed neurochemical or neurological basis. Despite considerable progress in brain imaging (Filipek et al, 1996; Castellanos et al, 1995 and 1996; Giedd et al, 1994; Semrud-Clikeman et al, 1994; Hynd et al, 1990 and 1994; Zamtekin et al, 1990 and 1993) and molecular biology (Cook et al, 1995; LaHoste et l, 1996), the clinical use of such tests is not yet available.

Until then, I recommend the following:

- a consensus on the prevalence should be reached, and this should be set in lower range of estimates (3% to 5%) rather than in the higher range (15% to 20%).

- guidelines should be set to constrain the use of subjective instruments (i.e., rating scales and clinical interviews).

- the limiting criteria of DSM-IV to define symptom presence (i.e., early onset, presence in more than one setting, and functional impairment) should be required.

- tests with relatively high false positive and false negative rates should not be used for screening or for routine clinical assessment.

C. What Is the Proper Treatment of ADHD?

We know from over a half century of clinical experience and extensive research that stimulant medications (amphetamine, methylphenidate, and pemoline) are effective in the short-term. I performed a review for the Department of Education of over 9,000 articles, which indicated what should be expected of treatment with stimulants (e.g., reduced manifestation of symptoms of hyperactivity, inattention, and impulsivity and associated features of aggression and defiance) and what should not be expected (e.g., paradoxical response, long-term effects on academic achievement or social adjustment, lack of side effects).

Long-term effects may require multi-modality treatment (Satterfield et al, 1979, 1980, 1987, 1995), but this is only now being put to a rigorous test by a multisite study funded by NIMH and DOE (Richters et al, 1996).

Typically, multimodality treatment is recommended (Swanson et al, 1993). The Department of Education commissioned a review (Fiore et al, 1993) which identified educational and other psychosocial treatment that are "promising", and behavioral interventions in the home (via parent training) and in the school (through token systems and daily report cards) were suggested as the most effective. Presently, most children with the ADHD diagnosis receive treatment with stimulant medication (i.e., 80%) but few receive behavioral intervention (i.e., 15%). Therefore, I believe that increased psychosocial intervention, especially in the school, should be made available. This is particularly important for children with concurrent symptoms of aggression and defiance (Satterfield et al, 1995).

Mr. SHAYS. Thank you, Dr. Swanson. Ms. Conrad.

Ms. CONRAD. Mr. Chairman and members of the subcommittee, thank you for inviting me to speak to you today on the very important issue of the attention deficit disorder with and without hyperactivity and to discuss the impact of this condition on the students who personally suffer from its effects and in the classrooms they attend. I've been employed with Toledo Public Schools in Toledo, OH, for the past 19 years. It's a large urban district serving approximately 39,000 students.

I have spent 19 years at that and 12 of those years were in severe behavior disabled, which is a term used by the Ohio Department of Education to describe severe emotional disturbances. Three additional years I spent teaching learning disabled students in a resource setting in an elementary building.

For the past 4 years, I have been a behavior specialist for the behavior specialist program. The behavior specialist program was instituted to address the overwhelming increase in teacher referrals for inappropriate, disruptive, and violent student behavior. We are teachers working with teachers to provide assistance in developing interventions to change behavior.

At the request of the teacher, we will come in, review the educational history, conduct an objective observation, meet with the teacher and the student to develop and implement the intervention. We then contact the parents and at that time contact counselors and their doctors at their request. Our involvement is normally 6 weeks in duration. Out of the 70 students that were on formal intervention last year, 11 were identified as ADD, ADHD.

The challenges facing teachers, because I'm in so many different buildings—we have 46 elementary buildings in Toledo. And last year, I was in 40 of them. With undiagnosed or untreated ADD, ADHD, I think we have to put them into three categories for me to explain. And they're all inter-related.

Social, academic, and behavioral.

Socially, many ADD, ADHD students have poor peer relationships, because of immature behaviors and social interests. They are excluded from peer groups by other students. As I go through these, really, my testimony on pages 2, 3, and 4 will cover it. I'm just going to go over some of the behaviors instead of reading every single behavior.

They tend to take inappropriate risks, and they have little regard for social consequences. Because of these factors, students with unrecognized or untreated ADD and ADHD experience poor self-concept.

Next, academic challenge, as these students generally lack organizational skills. Their assignments, too, are often incomplete or of poor quality or just plain missing. These demonstrate a lack of performance and not a lack of skill. In other words, these students may be very bright. They may have all of the skills they need to perform at their functional level.

Finally, I think the greatest challenge to the teachers is the behavioral aspect of this. These behaviors include defiance of authority, aggressiveness toward peers, and have a very low frustration tolerance. Again, you can refer to page 4 for the numerous other behaviors that I've seen.

What I'd like to do is give you a specific example—and I will call the student, Annie, that I worked with this year. She was in the first grade and I went out to do an observation. The noise level in the room was almost unbearable. Usually, when we do an observation, we stay in there minimally 60 to 90 minutes. She was rocking in her chair, talking to herself, chewing on her fingers, cutting up books, standing next to her chair, fiddling with pencils, constantly out of her seat without permission, ignoring teacher directives, directions.

The teacher assured me at our conference following that this is a typical day for Annie.

You can imagine the effect that that behavior would have on any class. Annie's very experienced, talented and dedicated teacher, who had managed many behavior problems in the past 18 years, had never experienced anything like Annie. And to say that she was frazzled and near nervous breakdown, she actually cried at our meeting.

When I was called in to assist her——

Mr. SHAYS. This is a teacher?

Ms. CONRAD. Yes. Yes. And I've seen this time and time again with several of the teachers that we've worked with. Even with interventions that allowed this teacher to regain some control, we set up a behavior management plan with tangible reinforcers, sticker chart, her behavior improved very minimally. It was just not acceptable in a classroom setting.

Yet, Annie's parents, persuaded by what they heard on television and what they read in the newspaper were convinced that medication is for drug addicts and will make a zombie out of their daughter. Because of this, they refused to consult with a doctor, even though the school counselor, the school psychologist, the principal, and myself urged them to consult with their physician, for Annie's sake.

My biggest fear as a result of her self-esteem plummeting is that she will eventually be identified as a severe behavior disabled student maybe by third grade.

Magnifying this long list of social, academic, and behavioral challenges are the inconsistencies and administration sometimes of medication at home or prescriptions that lapse. On occasion, parents intentionally remove their children from medication in an attempt to have them identified for a special ed placement in order to receive SSI payments. Please understand that I have a great deal of empathy for the parents of these children, and most of the parents that I work with are very stressed, but very cooperative. They work with me and with the school and they really want the best for their child, both academically and behaviorally.

However, I'm here to provide you with a vision of the challenge that teachers face in working with students who are ADD, ADHD, and all of these factors play a part in creating the formidable task of educating ADD, ADHD students while still meeting the needs of the rest of the class.

The challenges presented by the increasing number of students with ADD and ADHD compound the frustration levels of teachers who are being overwhelmed by the ever-increasing demands that have been placed upon them. They are rightly expected to help

their students meet higher educational standards and increase their test scores. But they are also expected to teach students to avoid drugs and violence and to include students with a variety of disabilities and educational skills in their classrooms.

Teachers' responses to this crisis are varied. At first, they attempt to address the behaviors of untreated ADD and ADHD students in the traditional manner. These can include parent contact, office referrals, detentions, referrals to the counselor. We have what's called a student assistance team in our buildings at the building level with a school psychologist. All along, though, they're using what I call their own bag of tricks, their own personal approaches that have been successful over the years in working with behavioral problems in the classroom.

And it's at this critical point that our program is usually contacted when we see the referral. All else has proved unsuccessful. At this point, the teachers are extremely discouraged, compromising their ability to teach to their highest potential, further impeding the education of the rest of the class. Thirty other children are waiting to be educated. And the parents of these children often vent their anger and frustration directly at the classroom teacher concerning the time and energy being spent on one student. They do not believe that their children should be cheated out of a valuable education.

Early interventions are most effective in critically underfunded schools. However, large class sizes and minimal support staff at the elementary level are contradictory to the concept of early intervention. Many classroom teachers are familiar with attention deficit disorder. However, information about ADD competes with a barrage of information about many other educational issues. In addition, most of the information that is available through talk shows, newscasts, and weekly magazines is not based on good research reports.

Therefore, often, they do not have a thorough enough understanding of ADD, ADHD.

I must add that it's unfair to ask teachers to deal with all of the behaviors that children with behavior problems have, including those with ADD, ADHD exhibit while still attempting to minister to the academic needs of the rest of the students. In addition, they are faced with a public that does not believe that ADD, ADHD is a legitimate condition. People who have not experienced the presence of an untreated ADD student in a large classroom setting often contend that a firm hand will solve the problem. They don't see children like Annie, who truly can't control their extremely impulsive behavior and who roam about the room like an out-of-control wind-up toy.

In my opinion, it's a three-pronged approach that's necessary to achieve success behaviorally as well as academically. First, and most importantly, is a correct diagnosis and appropriate medical intervention. Second, behavior management systems implemented collaboratively with the parents in school and at home. And, finally, counseling should provide families with social skills training and coping strategies for dealing with the low self-esteem issues. At the very end of the statement is an illustration of what can occur when a student is properly diagnosed and properly treated.

I've attached two spelling tests that were written by a fourth grade student. One is not only a failing paper, but close to indecipherable. It was done in February of this past year. The other was quite readable and the student earned a 93.

I can't stress enough that these students, when they have been inadequately diagnosed and treated, can bring a classroom educational program to a screeching halt with the attendant loss in learning to everyone in the class.

Thank you.

[The prepared statement of Ms. Conrad follows:]

Mr. Chairman and Members of the Subcommittee on Human Resources and Intergovernmental Relations, thank you for inviting me to speak to you today on the very important issue of Attention Deficit Disorder, with and without Hyperactivity, and to discuss the impact of this condition on the students who personally suffer from its effects and on the classrooms they attend.

I have been employed with the Toledo Public Schools for nineteen years. For fifteen of those years, I taught in elementary and junior high special education classes. For twelve of those years, my students had been identified as severe behavior disabled, the term used by the Ohio Department of Education for students with severe emotional disturbances. For three years I served as a resource teacher for students with learning disabilities. For the last four years, I have been working as a Behavior Specialist in a program jointly developed by the Toledo Public Schools and the Toledo Federation of Teachers.

The Toledo Public Schools Behavior Specialist Program was instituted to address the overwhelming increase in teacher referrals for inappropriate, disruptive, and violent student behavior. The Program consists of teachers working with teachers to provide assistance in developing individual interventions which will motivate students to change their behavior. At the request of a teacher, we conduct an observation of a specific student, and review the student's cumulative educational history. We then meet with the student's teacher to develop an individual behavior management program, designed to assist that student to control the undesirable behavior. Following the meeting with the teacher, we meet with the target student, explain our role, and together with the teacher implement the plan. We contact the parents as well as any outside agencies involved, such

as therapists, doctors, or counselors. The school psychologist and principal are notified of our involvement and provided with copies of all paperwork. We return on a weekly basis to meet with the student and teacher to monitor and modify the plan as needed. Our involvement is minimally six weeks in duration.

Approximately 16% of the seventy students that I worked with during this past year were diagnosed by their doctors as having Attention Deficit Disorder. The information they used to make their diagnoses included the School Rating Form and Home Rating Form of the Attention Deficit Disorders Evaluation Scale that I provided to them[1]. In addition, I provided the doctor with the results of my formal observation and descriptions of any interventions that I developed.

Once a student is identified as either ADD or ADHD, and successfully maintained in their current educational placement, I contact the receiving teacher each Fall for a consultation, to monitor the progress of the student.

CHALLENGES OF TEACHING STUDENTS WITH ADD/ADHD

The challenges facing teachers of students with undiagnosed and/or untreated ADD and ADHD are numerous. These challenges fall into three categories: social, academic, and behavioral. All three of these categories are interrelated. However, for clarity I will discuss the three individually.

Social Challenges

Socially, many ADD/ADHD students have poor peer relationships, because of their immature behaviors and social interests. They are excluded from peer groups by

[1] These rating scales are published by Hawthorne Educational Services, Inc

other students, as well as the parents of those students, who don't want their children to be exposed to the inappropriate behaviors exhibited by students whose ADD or ADHD remain untreated. Such ADD/ADHD students tend to take inappropriate risks, are less likely to be able to understand the perspectives of others, are selfish, self-centered, and exhibit intrusive behaviors. They have little regard for social consequences, with the result that social consequences imposed by their teachers have little effect on their inappropriate behavior. Because of these factors, students with unrecognized or untreated ADD and ADHD experience poor self-concepts. Unfortunately, their difficult behavior makes it difficult to see their pain.

Academic Challenges

These students generally lack organizational skills. The impact of this can be seen most clearly on their academic performance. Their assignments are too often incomplete, of poor quality, or just plain missing. They often avoid tasks which require sustained mental effort, and lose things necessary for tasks. Their weak social skills, mentioned above, have the additional academic impact of making them unable to work well cooperatively. They are unable to listen or stay on task, appear to be constantly daydreaming or confused. Directions must usually be repeated. They must often be redirected to remain on task or to continue desired activities. All of these demonstrate a lack of performance, and not a lack of skill. In other words, these students may be very bright, and they may well have all the skills they need to have in order to perform at their functional level. However, their inability to concentrate and attend to the task at hand, usually means that their performance level is well below their skill level.

Behavioral Challenges

Finally, the greatest challenge to the teachers' ability to educate the students in the class is the inappropriate behavior of untreated ADD/ADHD students which disrupts the class and interferes with the educational program. These behaviors include:

- impulsiveness,
- defiance of any authority figure without fear of consequence;
- aggressiveness towards peers and adults;
- repeated talking-out,
- answering questions incorrectly because they do not wait to hear the entire question;
- constantly being out of their seats and/or out of their areas;
- inappropriate touching and/or grabbing of others;
- refusal to follow directions;
- fidgeting and squirming in their seats;
- difficulty waiting for turns,
- difficulty handling changes in the regular classroom or school routine;
- inability to make smooth transitions from one activity to another; and
- a low tolerance for frustration.

In addition, even when students with unrecognized or untreated ADD and ADHD earn the right to a leisure activity because they have finished a task or behaved appropriately, they find it difficult to enjoy this activity without disturbing everyone else in the class.

Let me give you an example. Let me tell you about Annie.

The day that I observed in Annie's (I have changed Annie's name for confidentiality purposes) first grade classroom, the noise level was almost unbearable.

Annie was rocking in her chair, talking to herself, chewing on her fingers, cutting up books, standing next to her chair, fiddling with pencils, constantly out of her seat without permission, and ignoring the teacher's directions. Annie never worked on her assignments. The teacher assured me that this was a typical day for Annie.

You can imagine the effect that such behavior would have on any class. Annie's very experienced, talented, and very dedicated teacher, who had managed many behavior problems in her classes during the 18 years she taught, had never experienced any child like Annie. When I was called in to assist her, the teacher was close to a nervous breakdown. Even with interventions that allowed this teacher to regain some control of her class, still Annie's behavior only minimally improved. It was still unacceptable. Yet Annie's parents, persuaded by what they hear on television and what they read in the newspaper, are convinced that such medication is for drug addicts, and will make a zombie out of their daughter. Because of this, they refused to consult with a doctor. Even though the school counselor, the school psychologist, the principal, and I urged them to consult with a physician for Annie's sake, they refused. I fear that by the third grade, Annie will be in so much social, academic and behavioral trouble, with the resulting plummet in self-esteem, that she will have to be placed in a classroom for what we call severe behavior disabled students.

Additional Concerns

Magnifying this long list of social, academic, and behavioral challenges are the inconsistencies in administration of medication at home, or prescriptions that lapse. This leaves the child without any medical intervention, and often leaves them at risk for disciplinary action due to aberrant behaviors. On occasion, parents intentionally remove

their child from the medication in an attempt to have them identified for a special education placement in order to receive SSI payments.

Please understand that I have a great deal of sympathy for the parents of these children. They also face tremendous daily challenges in living with their ADD children. Most of the parents that I work with are very stressed but also very cooperative. They work with me and with the school, and they really want the best for their child -- both academically and behaviorally. I do not wish to sound anti-parent. It is certainly understandable that many of them are wary of over-medicating their children, or even of giving them medications they do not wholly understand. However, I am here to provide you with a vision of the challenges that teachers face in working with students who have ADD/ADHD, and all of these factors play a part in creating the formidable task of educating ADD and ADHD students while still meeting the needs of other students.

Educational Context of the Challenge

The challenges presented by increasing numbers of students with ADD and ADHD compound the frustration levels of teachers who are being overwhelmed by the ever-increasing demands being placed upon them. They are rightly expected to help their students meet higher educational standards and increase their test scores, but they are also expected to teach students to avoid drugs and violence, and to include students with a variety of disabilities and educational skills in their classrooms. The demands of untreated ADD and ADHD students have a highly negative impacts on attempts to provide a highly demanding learning environment because they make it extremely difficult to meet the educational needs of all the other students.

Teachers' Responses

Teachers' responses to this crisis are varied. At first, they attempt to address the behaviors of untreated ADD and ADHD students in a traditional manner. These may include contacting the parents, office referrals, detentions, referrals to the counselor, school psychologist, or, if it exists, the Student Assistance Team. All along, teachers are also utilizing their personal approaches that have succeeded over the years with other students. When all of these prove unsuccessful, the last resort for dealing with the behavior is suspension. This excludes the student totally from a learning environment, further weakening their academic performance. However, the teacher has the responsibility to act so that the student's behavior does not continue to disrupt the education of the other students.

It is at this critical point that we Behavior Specialists receive these referrals. All else has proven unsuccessful. At this point, teachers are extremely discouraged, compromising their ability to teach to their highest potential, and further impeding the education of the rest of the class. Thirty other children are waiting to be educated, and the parents of these children often vent their anger and frustration directly on the classroom teacher concerning the time and energy being spent on one student. They do not believe that their children should be cheated out of valuable learning time.

Early Intervention

The sooner we begin to address the problems of these children, the sooner we will put them on a track to success in school, and reclaim the classroom for their classmates. Early interventions are more cost effective in critically-underfunded schools. However,

large class sizes and minimal support staff at the elementary level are contradictory to the concept of early intervention.

WHAT DO CLASSROOM EDUCATORS KNOW?

Many classroom teachers are familiar with Attention Deficit Disorder, and with the beneficial effects of many of the medications that are prescribed. However, information about ADD competes with a barrage of information about many other educational issues. In addition, much of the information that is available is from talk shows, newscasts, and weekly magazines; it is not based on good research reports. Therefore, often teachers do not have a thorough understanding of ADD/ADHD.

In addition, they often do not have a repertoire of appropriate interventions to manage the untreated or unsuccessfully treated behavior of these students. Certainly teachers would be assisted if they had access to more research-based information such as that provided by the Office of Special Education Programs, and were able to learn strategies to deal with low levels of this behavior. I must add further, however, that it is unfair to ask teachers in general education classrooms to deal with all of the behaviors that children with behavior problems, including those with ADD/ADHD, exhibit while still attempting to minister to the academic needs of the rest of the students.

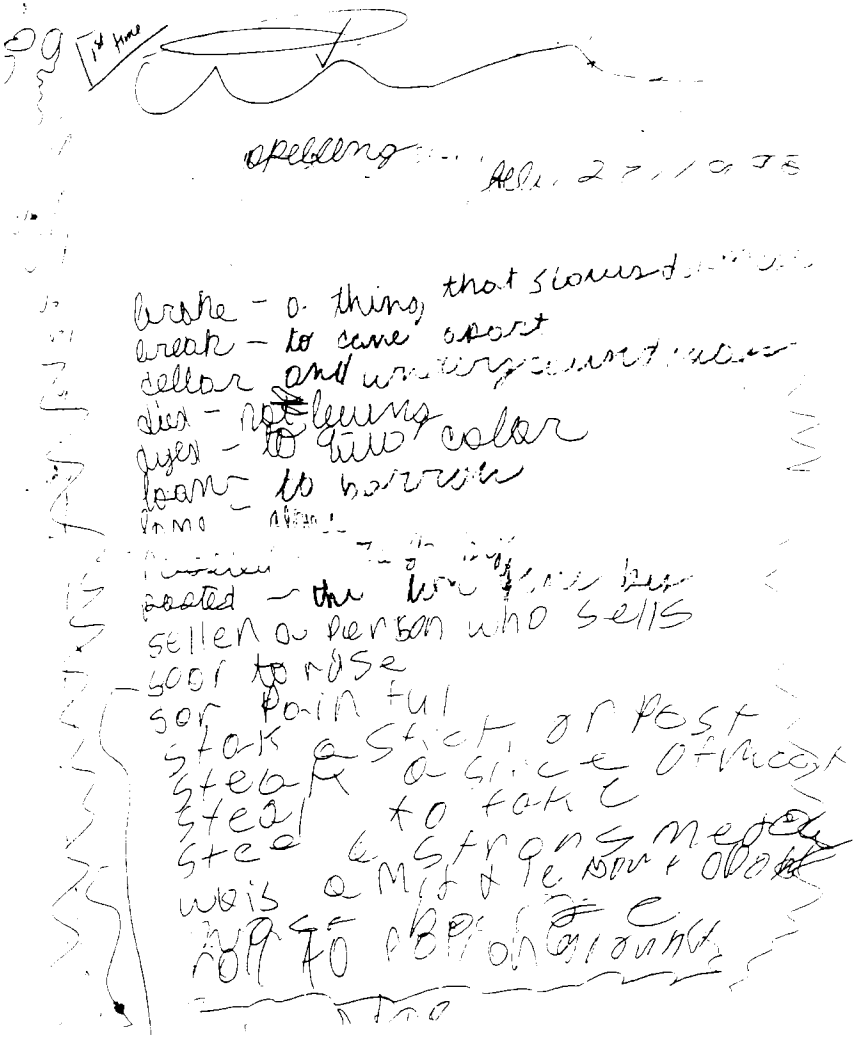
In addition, teachers are faced with a public that does not believe that ADD/ADHD is a legitimate condition. People who have not experienced the presence of an untreated ADD/ADHD student in a large classroom setting often contend that a "firm hand" will solve the problem. They do not see children like Annie who truly can't control their extremely impulsive behavior and who whirl around the room like an out-of-control wind-up toy.

RECOMMENDATIONS

A three-pronged approach is necessary to achieve success behaviorally and academically.:

- First and most importantly, correct diagnosis and appropriate medical intervention.
- Second, behavior management systems implemented collaboratively with classroom staff and parents in school and at home. Behavior management with ADD/ADHD children involves quick, frequent feedback at their levels of functioning which reinforces productive behavior. ADD/ADHD is a chronic disorder which requires long-term monitoring and maintenance. Since this is a motivational disorder, when the behavior management is discontinued, the inappropriate behavior resurfaces.
- Finally, counseling should provide families with social skills training and coping strategies for dealing with low self-esteem issues.

As an illustration of what can occur when a student is properly diagnosed and treated, I have attached two spelling tests that were written by a fourth-grade student. One is not only a failing paper, it is indecipherable. The other is quite readable -- and earned this student a 93. I do not suggest to you that medicine is always the correct solution, or that there are not students who are medicated who should not be. There are many problems of ADD and ADHD and its treatments that must be studied closely. However, I cannot stress enough that these students, when they have not been adequately diagnosed and treated, can bring a classroom educational program to a screeching halt -- with the attendant loss in learning to everyone in the class.



−3
93%
A

Spelling

april 19 1996

1. Thursday
2. August
3. Calendar
4. February
5. Tuesday
6. January
7. December
8. Sunday
9. March
10. Friday
11. October
12. Wednesday
13. July
14. Monday Monday
15. May
16. April
17. Saturday
18. June
19. November
20. February

1. Easter
2. Christmas
3. Chanukka
4. Thanksgiving
5. Passover

The calender shows Saturday as the last day of the week.

Mr. SHAYS. Thank you. I just want to ask a question. I won't think to ask it later on, because it relates to one point. You gave your three—you said three-prong approach. You said, correct diagnosis, behavioral management?

Ms. CONRAD. I'm saying the first would be correct diagnosis with appropriate medical intervention.

Mr. SHAYS. With appropriate medical intervention. Thank you. That's what I wanted to know. Dr. Zarin.

Dr. ZARIN. Thank you. Chairman Shays and members of the subcommittee, I'd like to thank you for the opportunity to talk to you today about attention deficit hyperactivity disorder or ADHD. I'm Deborah Zarin, deputy medical director of the American Psychiatric Association and a child and adolescent psychiatrist by training.

I appear to you today on behalf of both the American Psychiatric Association and the American Academy of Child and Adolescent Psychiatry. The American Academy of Child and Adolescent Psychiatry is a national association of over 6,000 child and adolescent psychiatrists or physicians with up to 5 years of special training in treating the mental illnesses of childhood and adolescence.

The American Psychiatric Association is a medical specialty society representing more than 40,000 psychiatric physicians nationwide.

Both medical specialty associations appreciate this public examination of ADHD. I have submitted written testimony and would like to make just a few brief comments today.

The first has to do with the assessment and diagnosis of this condition. Appended to my testimony are the diagnostic and statistical manual fourth edition criteria for ADHD. I believe these are the diagnostic criteria that Dr. Jensen and others were referring to when they talked about how the disorder is properly diagnosed.

It is important to note when looking at these criteria that they are meant to be applied by trained clinicians who can determine whether the characteristics are there—in other words, specific characteristics are listed as diagnostic criteria, trained clinicians can determine whether the characteristics that are seen may be better accounted for by either a variation of normal or by another disorder that requires attention.

And, finally, you can determine whether the symptoms are clinically significant. This is very important for when people would look at the DSM diagnosis, the diagnostic criteria and say, oh, that describes half the children in a playground. It is important to note that the criteria was meant to be applied by trained clinicians.

Both under and overdiagnosis are possible if these criteria are applied by untrained people. And this has, of course, been mentioned by many people in today's hearings. I'd like to comment on treatments now. There is clear evidence in the literature, as you have also heard, that there is a role for medication in treating this disorder and that there is a role for psychosocial treatments. In other words, both types of treatments have been shown to be effective in numerous studies.

Research is ongoing into the optimal application of these treatments. However, even now, there is consensus among trained clinicians about optimal treatment. And, unfortunately, optimal treatment is not always applied, as we have heard.

Although professional organizations and others are developing and have written guidelines regarding the application of these treatments, no guidelines replace the individual judgment of professionals who consider the particular clinical circumstances and make appropriate treatment recommendations for a particular child.

Finally, I have a few recommendations for public policy. I believe that it is critical to support the access to fully trained professionals for adequate assessment and diagnosis. And I believe everybody who has spoken to you today has mentioned this point.

Second, to support the access to all potentially effective treatments, so that the clinical decisionmaking for an individual child can be based on what's best for that individual child, not on what might be covered by a specific school system or might be covered by a particular health plan. And, finally, it's important to support ongoing research so that we can better understand the ideology of this disorder, better develop even better treatments and better develop guides to matching particular treatments to the particular needs of individual children.

And, of course, I would be happy to answer any questions. Thank you.

[The prepared statement of Dr. Zarin follows:]

UNITED STATES HOUSE OF REPRESENTATIVES

SUBCOMMITTEE ON HUMAN RESOURCES

AND

INTERGOVERNMENTAL RELATIONS

COMMITTEE ON GOVERNMENT REFORM AND OVERSIGHT

American Academy of Child and Adolescent Psychiatry

American Psychiatric Association

July 16, 1996

INTRODUCTION

Chairman Shays and other members of the Subcommittee on Human Resources and Intergovernmental Relations, thank you for the opportunity to submit this testimony about the childhood mental disorder known as attention-deficit/hyperactivity disorder or ADHD.

This statement is submitted by the American Academy of Child and Adolescent Psychiatry (AACAP) and the American Psychiatric Association (APA). The AACAP is a national, professional association of over 6,000 child and adolescent psychiatrists, who are physicians with up to five years of special training in treating the mental illnesses of childhood and adolescence. The American Psychiatric Association is a medical specialty society, representing more than 40,000 psychiatric physicians nationwide. Both medical specialty associations appreciate this public examination of ADHD, a serious mental disorder which has its onset in childhood, and if left untreated, will detract from a normal childhood and adult life. Research on this disorder is ongoing and exciting new findings are expected. This statement represents basic background information rather than the final word on diagnosis and treatment of ADHD. The AACAP and the APA understand the importance of supporting the work of federal agencies such as the National Institute of Mental Health and the Department of Education in the research efforts and the communication of information to the public.

It is important that this hearing presents the facts about ADHD. The periodic waves of media

attention questioning this disorder's prevalence and treatment are confusing to the public and understandably perplexing to legislators. Some reports on ADHD are carefully researched, balanced articles, defining the disorder and its treatment and educating readers. Other publications have caused confusion and spread misinformation. This hearing can make legislators and the public better able to judge the validity of information and clarify the myths about mental disorders such as ADHD.

EPIDEMIOLOGY OF ADHD

United States

Current estimates indicate for children with ADHD, 10 percent are boys and 2 percent are girls, with a general prevalence rate of an estimated 6 percent of the school-age population in the United States. There is a strong male predominance, with an almost 10 to one ratio for diagnosis boys to girls. The reported number of people with ADHD in the United States was over 2 million in 1995, up from 900,000 in 1990. The rapid increase in these numbers and in the prescribing of medications, specifically Ritalin, for the treatment of ADHD, has raised questions about accurate diagnosis and treatment. Medical associations such as the American Academy of Child and Adolescent Psychiatry, the American Psychiatric Association and the American Academy of Pediatrics have developed or are developing guidelines for diagnosing and treating ADHD. The AACAP has developed educational materials for parents and educators to help them understand this disorder and judge the accuracy of the diagnosis and the course of the treatment plan. Because child and adolescent psychiatrists are the only medical specialty with specific training in the diagnosing of childhood and adolescent mental illnesses, a special effort has been taken by the AACAP to inform the public and the media about ADHD.

Other countries

The United States has a higher reported prevalence of ADHD than do other countries. This difference may be due to increased environmental toxins (such as lead-containing gasoline, paints, and synthetic food additives) but could also be due to diagnostic practices. The expectations of educators and parents have also been raised as a possible reason for the disparity; parents provide less discipline to their children than parents in other countries, but they expect stable, mature behavior from these children.

In England, about two percent of child psychiatric outpatients have a diagnosis of ADHD (versus 40 percent in the United States). However, children with ADHD and conduct disorder would be diagnosed with conduct disorder in England and with ADHD (with secondary or associated conduct disorder) in the United States. Conduct disorder features a pattern of behavior where the rights of others or normal social rules are violated. This difference reflects the American emphasis on biological causes and drug treatment of ADHD, and the British emphasis on social causes and psychological treatment of conduct disorder.

STATUS OF UNDERSTANDING AND DIAGNOSING ADHD AND LEARNING DISABILITIES

Ten to twenty percent of the school-age population has an abnormal difficulty with academic

work. These youngsters fall into several broad categories: (1) some have mental retardation -- that is, they have subnormal intellectual capacities, and therefore they will always function below normal levels; (2) some have emotional problems that stand in the way of learning and cause academic difficulties; and (3) some have average or above-average intelligence, but still have academic difficulties because of the way their brain or nervous system functions. Although such children may have problems with physical disabilities such as impaired vision, hearing, or both, their learning problems are not caused by these impairments. The person we call "learning disabled" falls into this third group, often called the "neurological group." They represent between 3 and 10 percent of the school-age population. (Silver)

Children and adolescents with learning disabilities may have one or more of a group of associated disorders. ADHD also falls within this group of neurologically-based disorders. Some individuals with ADHD or a learning disability might have a tic disorder called Tourette's disorder; some may have an obsessive-compulsive disorder; and, some may have a seizure disorder. Most develop secondary emotional, social, and family problems because of the frustrations and failures they experience. These emotional, social, and family problems are referred to as "secondary" to emphasize that they are the consequence of the academic difficulties and not the cause of the difficulties. (Silver)

Often, more than one of these problems will occur in the same child. Diagnosing the specific disorder and any secondary disorder is tremendously important and must be done by professionals, such as child and adolescent psychiatrists, who have special training to accurately assess the symptoms as they appear in all areas of the child's life. For ADHD, the most frequent pattern found is associated learning disabilities and secondary emotional, social, and family problems. (Silver)

TERMINOLOGY HISTORY

In the early 1940s, a fourth group was identified; children who had difficulty learning because of a presumed problem with their nervous system. The initial researchers noted that these students had the same learning problems as individuals who were known to have brain damage (e.g., after trauma or surgery to the brain). Yet, these students looked normal; thus, it was considered that they also had brain damage, but that the damage was minimal. The term *minimal brain damage* was introduced.

Gradually, observations and testing revealed that no evidence of damage to the brain could be found in most of these children. In fact, research began to point to the idea that the cause of the problem lay in how the brain functions -- a physiologic and not structural problem. All of the brain mechanisms are present and operable, but some of the "wiring" is hooked up differently and, thus, does not work in the normal way. In the 1950s, the term *minimal brain dysfunction*, was used to identify children with learning difficulties, including hyperactivity. Professionals from different disciplines began the contemporary research that would lead to the diagnosis of ADHD. The labeling of disorders from this research caused some confusion since different disciplines used different terms, including dyslexia, dysgraphia and dyscalculia, but eventually the primary term became *learning disability*. In 1968, professionals studying children with

hyperactive, distractible behavior established the medical classification system as *hyperkinetic reaction of childhood.*

By 1980, that term was changed to attention-deficit disorder (ADD). In 1987, the term attention-deficit/hyperactivity disorder (ADHD) replaced attention-deficit disorder and was accepted as the classification for children who have distractibility, but ADHD can include inattention as a primary issue. The term ADD no longer exists. The rapid changes in terminology indicate the intensity of research into this childhood disorder. With continued support, research efforts should deliver new insights and terminology on a regular basis. (Silver)

We now know that learning disabilities and ADHD are two separate but related disorders, and that academic difficulties caused by other emotional, social, and/or family problems are also diagnosed and treated differently. We also know that children with auditory or visual problems can exhibit the symptoms of ADD, and the mental disorder diagnosis can be applied mistakenly when clinicians do an insufficient assessment and analysis of all the symptoms. The importance of accurate diagnosis cannot be overstated.

RECOGNITION AND DIAGNOSIS OF ADHD

One of the primary reasons for this hearing is to examine the increase in the numbers of children and adolescents diagnosed with ADHD. One of the first areas to be examined is the accuracy of the diagnosis. The diagnosis of ADHD cannot be made using a simple checklist of symptoms or reacting to initial comments from a parent or a teacher.

We are learning from the ongoing research into ADHD how to more accurately diagnose the disorder, but there is no question that the diagnosis is the key to appropriate treatment and effective outcomes. Currently, a child who has ADHD has been diagnosed according to the following criteria:

DSM-IV Diagnostic criteria for Attention-Deficit/ Hyperactivity Disorder

A. Either (1) or (2):

(1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention
(a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities

(b) often has difficulty sustaining attention in tasks or play activities

(c) often does not seem to listen when spoken to directly

(d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)

(e) often has difficulty organizing tasks and activities

(f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or home work)

(g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)

(h) is often easily distracted by extraneous stimuli

(i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of **hyperactivity impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity
(a) often fidgets with hands or feet or squirms in seat

(b) often leaves seat in classroom or in other situations in which remaining seated is expected

(c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)

(d) often has difficulty playing or engaging in leisure activities quietly

(e) is often "on the go" or often acts as if "driven by a motor"

(f) often talks excessively

Impulsivity
(g) often blurts out answers before questions have been completed

(h) often has difficulty awaiting turn

(i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Research findings have clarified the characteristics of ADHD, resulting in more accurate diagnostic criteria and more accurate diagnosis. The correct diagnosis is key to appropriate treatment and effective outcomes. A child or adolescent with ADHD will have one or more of three types of disorders: hyperactivity, inattention (distractibility), and/or impulsivity. Some will have only one of these disorders; some will have two; some will have all three. Critical to the diagnosis is the understanding that ADHD is neurologically-based and, for most individuals, has been present since birth. Thus, the behaviors reflective of the disorder have been present throughout the child or adolescent's life and are present throughout each day; that is, they are *chronic and pervasive.*

This concept of chronic and pervasive behavioral patterns is critical to the diagnosis. Such emotional problems as anxiety or depression can result in an individual being restless, inattentive, and irritable (thus impulsive). Certain learning disabilities can result in an individual being inattentive. However, with anxiety, depression, or a learning disability, the hyperactivity, distractibility, and/or impulsivity begins at a certain time or occurs during certain situations. For example, a child is described as hyperactive and inattentive in the fourth grade. It is noted that no previous teacher described the child as such. A more detailed clinical exploration shows that the child's parents separated during the summer between third and fourth grade.

Research has clarified and corrected some of the misconceptions about ADHD. It used to be believed that all children "outgrew" ADHD by puberty. Longitudinal studies show that between fifty and seventy percent of children will continue to have ADHD as adults. Even for those who improve at puberty, the residual emotional, social, and family problems might persist into adolescence and adulthood if not addressed. It is now understood that in about fifty percent of individuals, ADHD is inherited. Thus, there is a high likelihood that one or both parents also have ADHD or had ADHD as a child. Perhaps some of these studies suggesting parents of children with ADHD have a higher probability of emotional and work difficulties is explained by their unrecognized ADHD.

Another set of research findings suggest that girls with ADHD are more likely to be missed than boys. These findings are especially true for girls who are only inattentive. Boys, when struggling and frustrated, are more likely to act out and misbehave; thus, boys are more likely to be evaluated. Girls, under the same conditions, are more likely to become passive and

withdrawn; thus, they are missed.

THE OUTCOME OF ADHD

If a child or adolescent with ADHD is not identified and treated, he or she is at great risk for developing serious emotional or behavioral problems. Being unable to attend to learning, there is the risk of academic underachievement and failure. These problems increase during adolescence. Some outcomes studies on these unrecognized individuals suggest a higher risk of school drop out, delinquency, or other serious problems. Thus, it is critical that the individual be identified and diagnosed early. With the proper treatment, the outcome is much more likely to be positive.

TREATMENT OF ADHD

The treatment of ADHD must involve several models of help, including individual and family education, individual and family counseling, the use of appropriate behavioral management programs and the use of appropriate medications. Such a multimodal approach is needed because children and adolescents with ADHD frequently have multiple areas of difficulty. As with learning disabilities, the total person must be understood in his or her total environment. Educators, family members and others around a child with ADHD have to understand what is causing the distractibility, loss of concentration, frustration and depression linked to this disorder. They need counseling about how to create a good learning environment, to give instructions, to modify behavior when it becomes inappropriate and offer praise for good behavior. (Silver)

Medication to treat ADHD must be seen as part of a multimodal approach that also includes education, counseling, and behavioral management. If the clinician establishes this diagnosis, it is presumed that the behaviors are neurologically based. Therefore, since ADHD is not a school disability but a life disability, the need for medication must be assessed for each hour of each day. To place a child or adolescent on medication only during school hours on school days will result in the individual doing better in school. However, he or she may continue to have difficulties within the family and in interactions with peers. Medication holidays, which were used to counter fears that the drugs would stunt growth or cause other physical complications, are no longer a treatment recommendation. (Silver)

There are more than 200 studies showing that a stimulant called Ritalin (generic name: methylphenidate) works effectively for children with ADHD. Stimulants have been used in the treatment of ADHD for more than 90 years. Adults feel more focused and alert after a cup of coffee in the morning. This is basically how Ritalin works for children with ADHD. Ritalin and other stimulants increase the alertness of the brain and nervous system, stimulating it to produce more dopamine and norepinephrine. The medication increases the child's attention and reduces excess fidgetiness and hyperactivity, allowing him to focus on his work. Children with ADHD who take Ritalin make fewer errors on a variety of tasks than untreated children do. They are less impulsive and more attentive, both in the classroom and in social situations. (Koplewicz)

A myth surrounding the treatment of ADHD is the "paradoxical calming effect" of stimulants such as Ritalin. It is a commonly held misconception that if a stimulant calms a child, then he must have ADHD; if he didn't have the disorder, the thinking goes, the medication would not have any effect. That is not true. Stimulants increase attention span in normal children as well as those with ADHD.

A child should have had a complete physical examination within the last year before a stimulant is prescribed. This baseline of the physical condition will be used for comparison when the medication is taken over time. Most children should take ADHD medication for a minimum of nine to twelve months. There are medications other than Ritalin prescribed for ADHD, but it is the first choice for effective treatment. (Koplewicz) Ritalin is also the focus of media attention because of the increase in the number of prescriptions written over the last five years. Oversight of this increase should involve an examination of who is prescribing the medication, what diagnosic method was used to establish the disorder, and what does the treatment plan involve other than the medication.

TREATMENT PROVIDERS

Currently, treatment for children and adolescents with ADHD can be provided by primary care physicians or by specialists, including child and adolescent psychiatrists, psychiatrists, neurologists, and pediatricians. Other mental health providers who can treat ADHD but do not prescribe medications are psychologists, social workers, and school psychologists.

Different medical specialists see substantially different sectors of the ADHD population. Neurologists tend to see children with ADHD who have seizures and mental retardation. Psychiatrists treat ADHD with personality disorders and concomitant psychiatric illnesses, and child and adolescent psychiatrists are trained to treat specific child and adolescent characteristics and levels of severity. Pediatricians typically treat children with ADHD who have less severe characteristics.

ARE WE OVER DIAGNOSING ADHD?

About ten to fifteen years ago a concerted effort was made to educate professionals, parents, and teachers about ADHD. There was concern that too many children in adolescence were missed. A national parent organization, Children and Adults with Attention Deficit Disorder (CHADD), was formed along with other regional organizations. Literature became available to parents and teachers explaining ADHD. Books for the public were written and published. The topic of ADHD became popular in both the print and electronic media.

As a result, more children and adolescents have been diagnosed with ADHD. With the increased awareness that the disorder can continue into adulthood, more adults have been diagnosed . The general opinion is that more cases are being diagnosed because parents and teachers are recognizing the behaviors and referring to physicians and because more physicians are correctly making the diagnosis.

Studies at the American Psychiatric Association and elsewhere are currently underway to examine the treatment patterns of psychiatry, child and adolescent psychiatry, and other physicians for patients with ADHD. Studies of longer-term outcomes are also being developed.

RECOMMENDATIONS

The American Academy of Child and Adolescent Psychiatry and the American Psychiatric Association submit the following recommendations for the subcommittee's consideration in its report on "The Current Approaches of the Department of Education and the National Institute of Mental Health Regarding Diagnosis and Treatment of Attention-Deficit Hyperactivity Disorder":

- Support insurance benefit coverage under all health care systems for the diagnosis and treatment of ADHD.
- Support research into ADHD and other childhood mental disorders for both boys and girls.
- Support integrated services systems for delivering treatment for mental illnesses.
- Support legislation that assists children, adolescents and their families when ADHD disrupts their lives; oppose legislation that recognizes only the behavior and offers punitive resolutions rather than recognizing the reasons for the behavior and offering help through federal health and education services.
- Support clinical trials for medications prescribed for children.
- Support the development and distribution of educational information to parents, educators, primary care physicians, and the general public.
- Support the distribution of guidelines for diagnosing and treating ADHD.
- Support surveys and evaluations which provide updated data on the numbers of children and adolescents diagnosed with ADHD, prescriptions written by geography and specialty.

SUMMARY

The prevalence rate for children and adolescents with mental disorders is approximately 12 percent, with 7 to 12 million American youngsters needing treatment and services at any one time. Only a small percentage of these children ever receive any treatment or find their way into a service system that can meet their needs. This prevalence rate has not changed significantly for over a decade, yet we are here discussing whether there may be too many diagnoses of ADHD and too many prescriptions for Ritalin. It is appropriate to look into an issue that receives this much attention, but it is also appropriate to remember that concerns about overdiagnosis can be addressed with better education about the disorder, better training for the providers of treatment, more research into the diagnosis and treatment, and a comprehensive service delivery system.

No one -- not children, adolescents or adults -- can be assured an early identification, accurate diagnosis and appropriate treatment until the skills, resources, and governmental support are available. Too many families have to deal with mental illnesses without support, diagnosis, treatment or resources to buy medications.

Thank you for this opportunity to focus on the steps we can take to assure an accurate diagnosis for children and adolescents with ADHD.

G:\USERS\MPC\ADHD.96
D12

REFERENCES

American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders, fourth edition*, Washington, DC, American Psychiatric Association, 1994.

Koplewicz, Harold S., *It's Nobody's Fault, New Hope, and Help for Difficult Children and Their Parents*, Times Books, 1996.

National Institute of Health, National Institute of Mental Health: *Attention Deficit Hyperactivity Disorder*, NIH 94-3572, 1994.

Silver, Larry B., *The Misunderstood Child, A Guide for Parents of Children with Learning Disabilities - 2nd Edition*, Human Services Institute and TAB Books, 1992.

Silver, Larry B., *Attention Deficit Hyperactivity Disorder: A Clinical Guide to Diagnosis and Treatment,* written for clinicians. *APA Press, 1992.*

Silver, Larry B., *Dr. Larry Silver's Advice to Parents on Attention Deficit Hyperactivity Disorder,* written for parents. *APA Press, 1992*

Talbot, John A., Hales, Robert E, Yudofsky, Stuart, C., *Textbook of Psychiatry*, American Psychiatric Press, 1988.

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS FOURTH EDITION

Attention-Deficit/Hyperactivity Disorder

Diagnostic Features

The essential feature of Attention-Deficit/Hyperactivity Disorder is a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development (Criterion A). Some hyperactive-impulsive or inattentive symptoms that cause impairment must have been present before age 7 years, although many individuals are diagnosed after the symptoms have been present for a number of years (Criterion B). Some impairment from the symptoms must be present in at least two settings (e.g., at home and at school or work) (Criterion C). There must be clear evidence of interference with developmentally appropriate social, academic, or occupational functioning (Criterion D). The disturbance does not occur exclusively during the course of a Pervasive Developmental Disorder,. Schizophrenia, or other Psychotic Disorder and is not better accounted for by another mental disorder (e.g., a Mood Disorder, Anxiety Disorder, Dissociative Disorder or Personality Disorder) (Criterion E).

Inattention may be manifest in academic, occupational, or social situations. Individuals with this disorder may fail to give close attention to details or may make careless mistakes in schoolwork or other tasks (Criterion A1a). Work is often messy and performed carelessly and without considered thought. Individuals often have difficulty sustaining attention in tasks or play activities and find it hard to persist with tasks until completion (Criterion A1b). They often appear as if their mind is elsewhere or as if they are not listening or did not hear what has just been said (Criterion A1c). There may be frequent shifts from one uncompleted activity to another. Individuals diagnosed with this disorder may begin a task, move on to another, then turn to yet something else, prior to completing any one task. They often do not follow through on requests or instructions and fail to complete schoolwork, chores, or other duties (Criterion A1d). Failure to complete tasks should be considered in making this diagnosis only if it is due to inattention as opposed to other possible reasons (e.g., a failure to understand instructions). These individuals often have difficulties organizing tasks and activities (Criterion A1e). Tasks that require sustained mental effort are experienced as unpleasant and markedly aversive. As a result, these individuals typically avoid or have a strong dislike for activities that demand sustained self-application and mental effort or that require organizational demands or close concentration (e.g., homework or paperwork) (Criterion A1f). This avoidance must be due to the person's difficulties with attention and not due to a primary oppositional attitude, although secondary oppositionalism may also occur. Work habits are often disorganized and the materials necessary for doing the task are often scattered, lost, or carelessly handled and damaged (Criterion A1g). Individuals with this disorder are easily distracted by irrelevant stimuli and frequently interrupt ongoing tasks to attend to trivial noises or events that are usually and easily ignored by others (e.g., a car honking, a background

conversation) (Criterion A1h). They are often forgetful in daily activities (e.g., missing appointments, forgetting to bring lunch) (Criterion A1i). In social situations, inattention may be expressed as frequent shifts in conversation, not listening to others, not keeping one's mind on conversations, and not following details or rules of games or activities.

Hyperactivity may be manifested by fidgetiness or squirming in one's seat (Criterion A2a) by not remaining seated when expected to do so (Criterion A2b), by excessive running or climbing in situations where it is inappropriate (Criterion A2c), by having difficulty playing or engaging quietly in leisure activities (Criterion A2d), by appearing to be often "on the go" or as if "driven by a motor" (Criterion A2e), or by talking excessively (Criterion A2f). Hyperactivity may vary with the individual's age and developmental level, and the diagnosis should be made cautiously in young children. Toddlers and preschoolers with this disorder differ from normally active young children by being constantly on the go and into everything; they dart back and forth, are "out of the door before their coat is on," jump or climb on furniture, run through the house, and have difficulty participating in sedentary group activities in preschool classes (e.g., listening to a story). School-age children display similar behaviors but usually with less frequency or intensity than toddlers and preschoolers. They have difficulty remaining seated, get up frequently, and squirm in, or hang on to the edge of, their seat. They fidget with objects, tap their hands, and shake their feet or legs excessively. They often get up from the table during meals, while watching television, or while doing homework; they talk excessively; and they make excessive noise during quiet activities. In adolescents and adults, symptoms of hyperactivity take the form of feelings of restlessness and difficulty engaging in quiet sedentary activities.

Impulsivity manifests itself as impatience, difficulty in delaying responses, blurting out answers before questions have been completed (Criterion A2g), difficulty awaiting ones turn (Criterion A2h), and frequently interrupting or intruding on others to the point of causing difficulties in social, academic, or occupational settings (Criterion A2i). Others may complain that they cannot get a word in edgewise. Individuals with this disorder typically make comments out of turn, fail to listen to directions, initiate conversations at inappropriate times, interrupt others excessively, intrude on others, grab objects from others, touch things they are not supposed to touch, and clown around. Impulsivity may lead to accidents (e.g., knocking over objects, banging into people, grabbing a hot pan) and to engagement in potentially dangerous activities without consideration of possible consequences (e.g., riding a skateboard over extremely rough terrain).

Behavioral manifestations usually appear in multiple contexts, including home, school work, and social situations. To make the diagnosis, some impairment must be present in at least two settings (Criterion C). It is very unusual for an individual to display the same level of dysfunction in all settings or within the same setting at all times. Symptoms typically worsen in situations that require sustained attention or mental effort or that lack intrinsic appeal or novelty (e.g., listening to classroom teachers, doing class assignments, listening to or reading lengthy materials, or working on monotonous, repetitive tasks). Signs of the disorder may be minimal or absent when the person is under very strict control, is in a novel setting, is engaged in especially interesting activities in a one-to-one situation (e.g., the clinician's office), or while the person experiences frequent rewards for appropriate behavior. The symptoms are more likely to occur in group situations (e.g., in playgroups, classrooms, or work environments). The clinician should therefore inquire about the

individual's behavior in a variety of situations within each setting.

Subtypes

Although most individuals have symptoms of both inattention and hyperactivity impulsivity, there are some individuals in whom one or the other pattern is predominant. The appropriate subtype (for a current diagnosis) should be indicated based on the predominant symptom pattern for the past 6 months.

314.01 **Attention-Deficit/Hyperactivity Disorder, Combined Type.** This subtype should be used if six (or more) symptoms of inattention and six (or more) symptoms of hyperactivity-impulsivity have persisted for at least 6 months. Most children and adolescents with the disorder have the Combined Type. It is no known whether the same is true of adults with the disorder.

314.00 **Attention Deficit/Hyperactivity Disorder, Predominantly Inattentive Type.** This subtype should be used if six (or more) symptoms of inattention (but fewer than six symptoms of hyperactivity-impulsivity) have persisted for least 6 months.

314.01 **Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive type.** This subtype should be used if six (or more) symptoms of hyperactivity-impulsivity (but fewer than six symptoms of inattention) have persisted for at least 6 months. Inattention may often still be a significant clinical feature in such cases.

Recording Procedures

Individuals who at an earlier stage of the disorder had the Predominantly Inattentive Type or the Predominantly Hyperactive-Impulsive Type may go on to develop the Combined Type and vice versa. The appropriate subtype (for a current diagnosis) should be indicated based on the predominant symptom pattern for the past 6 months. If clinically significant symptoms remain but criteria are no longer met for any of the subtypes, the appropriate diagnosis is Attention-Deficit/Hyperactivity Disorder, In Partial Remission. When an individual's symptoms do not currently meet full criteria for the disorder and it is unclear whether criteria for the disorder have previously been met, Attention-Deficit/Hyperactivity Disorder Not Otherwise Specified should be diagnosed.

Associated Features and Disorders

Associated descriptive features and mental disorders. Associated features vary depending on age and developmental stage and may include low frustration tolerance, temper outbursts, bossiness, stubbornness, excessive and frequent insistence that, requests be met, mood lability, demoralization, dysphoria, rejection by peers, and poor self-esteem. Academic achievement is often impaired and devalued, typically leading to conflict with the family and school authorities. Inadequate self-application to tasks that require sustained effort is often interpreted by others as indicating laziness, a poor sense of responsibility, and oppositional behavior. Family relationships are often characterized by resentment and antagonism, especially because variability in the individuals symptomatic status often leads

parents to believe that all the troublesome behavior is willful. Individuals with Attention-Deficit/Hyperactivity Disorder may obtain less schooling than their peers and have poorer vocational achievement. Intellectual development, as assessed by individual IQ tests, appears to be somewhat lower in children with this disorder. In its severe form, the disorder is very impairing, affecting social, familial, and scholastic adjustment. A substantial proportion of children referred to clinics with Attention-Deficit/Hyperactivity Disorder also have Oppositional Defiant Disorder or Conduct Disorder. There may be a higher prevalence of Mood Disorders, Anxiety Disorders, Learning Disorders, and Communication Disorders in children with Attention Deficit/Hyperactivity Disorder. This disorder is not infrequent among individuals with Tourette's Disorder; when the two disorders coexist, the onset of Attention-Deficit/Hyperactivity Disorder often precedes the onset of the Tourette's Disorder. There may be a history of child abuse or neglect, multiple foster placements, neurotoxin exposure (e.g., lead poisoning), infections (e.g., encephalitis), drug exposure in utero, low birth weight and Mental Retardation.

Associated laboratory findings. There are no laboratory tests that have been established diagnostic in the clinical assessment of Attention-Deficit/Hyperactivity Disorder. Tests that require effortful mental processing have been noted to be abnormal in groups of individuals with Attention-Deficit/Hyperactivity Disorder compared with control subjects, but it is not yet entirely clear what fundamental cognitive deficit is responsible for this.

Associated physical examination findings and general medical conditions. There are no specific physical features associated with Attention-Deficit/Hyperactivity Disorder , although minor physical anomalies (e.g., hypertelorism, highly arched palate, low set ears) may occur at a higher rate than in the general population. There may also be a higher rate of physical injury.

Specific Culture, Age, and Gender Features

Attention-Deficit/Hyperactivity Disorder is known to occur in various cultures, with variations in reported prevalence among Western countries probably arising more from different diagnostic practices than from differences in clinical presentation.

It is especially difficult to establish this diagnosis in children younger than age 4 or cause their characteristic behavior is much more variable than that of older children and may include features that are similar to symptoms of Attention-Deficit/ Hyperactivity Disorder. Furthermore, symptoms of inattention in toddlers or preschool children are often not readily observed because young children typically experience few demands for sustained attention. However, even the attention of toddlers can be held in a variety of situations (e.g., the average 2- or 3-year-old child can typically sit with an adult looking through picture books). In contrast, young children with Attention-Deficit/ Hyperactivity Disorder move excessively and typically are difficult to contain. Injuring about a wide variety of behaviors in a young child may be helpful in ensuring that a full clinical picture has been obtained. As children mature, symptoms usually become less conspicuous. By late childhood and early adolescence, signs of excessive gross motor activity (e.g., excessive running and climbing, not remaining seated) are less common, and hyperactivity symptoms may be confined to fidgetiness or an inner feeling of jitteriness or restlessness. In school-age children, symptoms of inattention affect classroom work and academic performance. Impulsive symptoms may also lead to the

breaking of familial, interpersonal, and educational rules, especially in adolescence. In adulthood, restlessness may lead to difficulty in participating in sedentary activities and to avoiding pastimes or occupations that provide limited opportunity for spontaneous movement (e.g., deskjobs).

The disorder is much more frequent in males than in females, with male-to-female ratios ranging from 4:1 to 9:1, depending on the setting (i.e., general population or clinics).

Prevalence

The prevalence of Attention-Deficit/Hyperactivity Disorder is estimated at 3% - 5% in school-age children. Data on prevalence in adolescence and adulthood are limited.

Course

Most parents first observe excessive motor activity when the children are toddlers, frequently coinciding with the development of independent locomotion. However, because many overactive toddlers will not go on to develop Attention-Deficit/Hyperactivity Disorder, caution should be exercised in making this diagnosis in early years. Usually, the disorder is first diagnosed during elementary school years, when school adjustment is compromised. In the majority of cases seen in clinical settings, the disorder is relatively stable through early adolescence. In most individuals, symptoms attenuate during late adolescence and adulthood, although a minority experience the full complement of symptoms of Attention-Deficit/Hyperactivity Disorder into mid-adulthood. Other adults may retain only some of the symptoms, in which case the diagnosis of Attention-Deficit/Hyperactivity Disorder, In Partial Remission, should be used. This diagnosis applies to individuals who no longer have the full disorder but still retain some symptoms that cause functional impairment.

Familial Pattern

Attention-Deficit/Hyperactivity Disorder has been found to be more common in the first-degree biological relatives of children with Attention-Deficit/Hyperactivity Disorder. Studies also suggest that there is a higher prevalence of Mood and Anxiety Disorders, Learning Disorders, Substance-Related Disorders, and Antisocial Personality Disorder in family members of individuals with Attention-Deficit/Hyperactivity Disorder.

Differential Diagnosis

In early childhood, it may be difficult to distinguish symptoms of Attention-Deficit/ Hyperactivity Disorder from **age-appropriate behaviors in active children** (e.g., running around or being noisy).

Symptoms of inattention are common among children with low IQ who are placed in academic settings that are inappropriate to their intellectual ability. These behaviors must be distinguished from similar signs in children with Attention-Deficit/Hyperactivity Disorder. In children with **Mental Retardation,** an additional diagnosis of Attention-Deficit/Hyperactivity Disorder should be made only if the symptoms of inattention or hyperactivity are excessive for the child's mental age. Inattention in the classroom may

also occur when children with high intelligence are placed in academically **under stimulating environments.** Attention-Deficit/Hyperactivity Disorder must also be distinguished from difficulty in goal-directed behavior in children from inadequate, disorganized, or chaotic environments. Reports from multiple informants (e.g., baby sitters, grandparents, or parents of playmates) are helpful in providing a confluence of observations concerning the child's inattention, hyperactivity, and capacity for develop mentally appropriate self-regulation in various settings.

Individuals with **oppositional behavior** may resist work or school tasks that require self-application because of an unwillingness to conform to others' demands. These symptoms must be differentiated from the avoidance of school tasks seen in individuals with Attention-Deficit/Hyperactivity Disorder. Complicating the differential diagnosis is the fact that some individuals with Attention-Deficit/Hyperactivity Disorder develop secondary oppositional attitudes toward such tasks and devalue their importance often as a rationalization for their failure.

Attention-Deficit/Hyperactivity Disorder is not diagnosed if the symptoms are better accounted for by **another mental disorder** (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, Personality Disorder, Personality Change Due to a General Medical Condition, or a Substance-Related Disorder). In all these disorders, the symptoms of inattention typically have an onset after age 7 years, and the childhood history of school adjustment generally is not characterized by disruptive behavior or teacher complaints concerning inattentive, hyperactive, or impulsive behavior. When a Mood Disorder or Anxiety Disorder co-occurs with Attention-Deficit/Hyperactivity Disorder, each should be diagnosed. Attention-Deficit/Hyperactivity Disorder is not diagnosed if the symptoms of inattention and hyperactivity occur exclusively during the course of a **Pervasive Developmental Disorder or a Psychotic Disorder.** Symptoms of inattention, or impulsivity related to the use of medication (e.g., bronchodilators, isoniazed akathisia from neuroleptics) in children before age 7 years are not diagnosed as Attention-Deficit/Hyperactivity Disorder but instead are diagnosed as **Other Substance-Related Disorder Not Otherwise Specified.**

Diagnostic criteria for Attention-Deficit/ Hyperactivity Disorder

A. Either (1) or (2):

(1) six (or more) of the following symptoms of **inattention** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention

(a) often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities

(b) often has difficulty sustaining attention in tasks or play activities

(c)often does not seem to listen when spoken to directly

(d) often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to oppositional behavior or failure to understand instructions)

(e) often has difficulty organizing tasks and activities

(f) often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or home work)

(g) often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)

(h) is often easily distracted by extraneous stimuli

(i) is often forgetful in daily activities

(2) six (or more) of the following symptoms of **hyperactivity impulsivity** have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity
(a) often fidgets with hands or feet or squirms in seat

(b) often leaves seat in classroom or in other situations in which remaining seated is expected

(c) often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)

(d) often has difficulty playing or engaging in leisure activities quietly

(e) is often "on the go" or often acts as if "driven by a motor"

(f) often talks excessively

Impulsivity
(g) often blurts out answers before questions have been completed

(h) often has difficulty awaiting turn

(i) often interrupts or intrudes on others (e.g., butts into conversations or games)

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.

C. Some impairment from the symptoms is present in two or more settings (e.g., at school [or work] and at home).

D. There must be clear evidence of clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g., Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Code based on type:

314.01 Attention-Deficit/Hyperactivity Disorder, Combined Type: if both Criteria A1 and A2 are met for the past 6 months

314.00 Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type: if Criterion A1 is met but Criterion A2 is not met for the past 6 months

314.01 Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type: if Criterion A2 is met but Criterion A1 is not met for the past 6 months

Coding note: For individuals (especially adolescents and adults) who currently have symptoms that no longer meet full criteria, "In Partial Remission" should be specified.

314.9 Attention-Deficit/Hyperactivity Disorder Not Otherwise Specified

This category is for disorders with prominent symptoms of inattention or hyperactivity impulsivity that do not meet criteria for Attention-Deficit/Hyperactivity Disorder.

Mr. SHAYS. Thank you. I want to just do the first and second panels. I noticed it was getting late and I didn't want to make anyone feel they had to stay. But I'm going to invite you to come up and make any comment you like if you would like to at the end, because we would like that part of the record.

First, Mr. Dwyer, I wrote myself a note about the medicating of these youngsters. I'm trying to remember what it was. Do you remember? Your bottom line point, it seems to me, is the most unique in this. You seem to be the one who is providing the most caution in terms of overdiagnosis. Would that be your assessment, given the testimony that you've heard today?

Mr. DWYER. Yes. I think I would be worried about us moving toward the trend of 6, 7, 8 percent of children being on medication. I think that that, to me, raises a very serious question as to whether or not we are using this diagnosis to cover a lot of other problems in our society.

We have an awful lot of cost-effective, easy-to-administer behavioral interventions that we should try with a lot of youngsters.

Mr. SHAYS. Premedication.

Mr. DWYER. Pardon me?

Mr. SHAYS. Premedication.

Mr. DWYER. Premedication. But I also believe that when it appears that the diagnosis is correct and medication is applied, then I think the combination with training and behavior inteventions has merit. Now, we're not there yet to see the longitudinal value of the combination in terms of our research. But from the experiential level, I think that's the way we should move.

Mr. SHAYS. Mr. Swanson, you had mentioned that the FDA adequately controls the use of drugs. And I didn't know in what context I should take it. When you say they adequately control the use of it, they approve the drug and they define how it can be used. But they're not—they're not weighing in right now in terms of whether there is overuse of particular drugs, are they?

Mr. SWANSON. No. I state this to you because I believe it and I don't want other people to be upset with me for saying this. But methylphenidate does have an abuse potential. And that's why it's a schedule II drug.

Mr. SHAYS. An addictive aspect to it?

Mr. SWANSON. It isn't abused and it isn't used that way. And one reason I think it's not is that it has been controlled and access to it has been limited. So my reference was to something that was controversial over the last year or so about whether this should be changed and made a schedule III drug instead of a schedule II drug. I think that the right decision was made and I think a lot of people in this room may disagree with me, but I think that we have a medication that's not abused even though we need to be cautious about its use, because it has abuse potential. And that's why I was saying the FDA, I think, has done a good job.

Mr. SHAYS. I had someone make the argument that if caffeine had not already been introduced into society today, it would not be allowed to be introduced in the wide measure that it is. That may seem like it's coming out of left field, but do you have any comment? Just to explain, I mean, I see 3-year-old children drinking

Coca-Cola and I'm thinking to myself, you know, why are parents letting their kids drink that stuff.

Mr. SWANSON. I don't think in this case they're the same—it's not the same level of concern about caffeine that we may have about medications like amphetamine and methylphenidate. So, no; I think that these drugs were approved for use long ago. And perhaps they didn't undergo the rigorous testing that a medication would undergo if it were to come on board now and be approved. But we have a long history of safety and of efficacy of these stimulant drugs, which you've heard about from a variety of individuals today. So it is absolutely essential for us to maintain access to these medications as one part of treatment.

And even if there is a tendency maybe to overuse medication in current times, it certainly has been demonstrated to be effective, not for all children. And, I think, it's only maybe 70 percent of the children with a diagnosis. But, certainly, that group needs the treatment with medication. And, I think, having access to it and at the same time, controlling it in some way to prevent its misuse is essential.

Mr. SHAYS. Can either of the first two witnesses, or any of the witnesses here, tell me if there are ongoing studies as to whether this is a problem that is more prevalent today or that was just not diagnosed in the past? In other words, is this a disorder that is becoming a greater concern and that was not—well, I asked my question.

Mr. SWANSON. I think the prevalence probably has not changed. The actual true prevalence, although there is some concern about how we actually determine what that true prevalence is. I think it's been constant. And there are references to attention deficit disorder like symptoms way back in history. But, certainly, we recognizing it more because it's become more accepted and caused—in one sense, parent groups have formed to look into services for children that are having severe problems. And many of those children have attention deficit disorder as their problem. And parent groups have, I think, been very interested in having this condition defined, having the information about it more accessible and making it more acceptable to admit that you have the disorder and seek treatment for it.

So, I think, that's one of the primary reasons, along with the change in educational law that we're seeing a lot more recognition of the disorder.

Mr. SHAYS. Ms. Conrad, let me get to you and then ask this next question after that to all of you. You mentioned that 16 percent of the 70 students that were being looked at ultimately were diagnosed with ADD or ADHD. What was—how did you define the remaining 84 percent of the students?

Ms. CONRAD. Well, out of the 70, 48 including the ADHD, 11, were maintained in their current placement. Three of them were identified as severe learning disabled or developmentally delayed.

Mr. SHAYS. And considered a more serious problem to deal with or less?

Ms. CONRAD. They were identified as that being the least restrictive environment under IDEA. They were tested. A complete multifactor evaluation was done via the psychologist and determined

that the least restrictive environment at that point, because of the ADD placement, developmental delay would have to be below a 80 in the State of Ohio IQ. And severe learning disabled was the other. And there were three of them.

Mr. SHAYS. You're using the least restrictive term. And I need to have you define that.

Ms. CONRAD. The least restrictive environment is where the—a most restrictive environment would be a separate facility where you're not even in a school building. When we have a psychologist become involved and have a student——

Mr. SHAYS. Is the goal to be in the least restrictive and this is why.

Ms. CONRAD. Right.

Mr. SHAYS. That's what I'm missing.

Ms. CONRAD. Right, closest to regular. The goal obviously is keep them regular.

Mr. SHAYS. Closest to normal or regular.

Ms. CONRAD. Exactly. To keep them in a regular classroom obviously would be the goal. And we had 10 out of those 70 identified as severe behavioral disabled, or as the Federal term, severe emotional disturbance. Four of them are awaiting a multifactor evaluation as of June at the end of the school year. And five moved away. Those are out of the 70 that I worked with.

And I think my percentage is higher, also, because our program is behaviorally oriented and I'm pulled in specifically for that reason. Some of them had to wait because we've only got two behavioral specialists for our entire district. We just hired one more in May 1996, though.

Mr. SHAYS. Let me ask you first and then others can respond to this question. Should I make the assumption that when someone is diagnosed with ADD or ADHD, that in every instance they will have a chemical protocol as well as a nonchemical protocol?

Ms. CONRAD. Well, I think that's controversial.

Mr. SHAYS. I'm asking Dr. Zarin.

Dr. ZARIN. You mean, whether if I thought they were getting optimal treatment, or whether optimal treatment would always include a medication?

Mr. SHAYS. Yes.

Dr. ZARIN. Is that what you're asking?

Mr. SHAYS. Yes.

Dr. ZARIN. No; I don't think optimal treatment needs to always include medication.

Mr. SHAYS. I mean, they've been diagnosed.

Dr. ZARIN. Yes. I hear your question. I think that the MTA study, the multimodal treatment of ADHD that Dr. Jensen and others mentioned might help us to decide which children would be best to offer the medication, which would be best off with the behavioral treatment and which would be best off with both. But at this point, I think that the optimal therapy to practice certainly allows for the fact that some children can be optimally managed and do their best without medication.

Mr. SHAYS. What has come through loud and clear with all three panels, I would like to know your concurrence, or not, has been

that the medical treatment is not a replacement for other behavioral efforts, like nonmedical treatment.

Dr. ZARIN. I think that the clinical consensus, I would say, at least among psychiatrists is that it's generally best combined, although it's possible that with the types of research studies that are going on, that we will be able to identify a group of children who would do just as well with medication alone, as they would with medication plus behavioral treatment.

But in the absence of that finding which we don't have yet, most people would recommend a minimum of combination.

Mr. SHAYS. So your testimony before this committee would be there would be instances where a chemical treatment would be simply adequate without any other type of treatment?

Dr. ZARIN. No. No. My testimony is that that's possible. We do not have that data in yet. At this point, I think that clinical consensus is that, in general, medication plus a psychosocial intervention would be better than medication without a psychosocial intervention.

Mr. SHAYS. This is a question. Dr. Jensen testified that the six-site treatment study being conducted by the Department of Education and NIMH would set the standard for the treatment of ADHD for the next decade. I hope that's a fair analysis. Thank you, Dr. Jensen.

Are any of your organizations contributing clinical research or other support to the study? And what is your view of the capacity of the study to redefine the treatment of ADHD?

Dr. ZARIN. I couldn't actually hear the last two phrases.

Mr. SHAYS. The first question was: Are any of your organizations contributing clinical research or other support to the study? And the second question is: What is your view of the capacity of the study to redefine treatment of ADHD?

Dr. ZARIN. I think that certainly members of both of the organizations that I represent are actively involved in the study. And my view is that the study is going to be quite clinical in defining the benefits of different types of treatment; and will, therefore, be critical.

In addition, the American Psychiatric Association is planning a study now that will look at the treatments that children and adolescents are receiving from psychiatrists in routine practice settings, not in specialized settings that they receive in this type of clinical trial. And I believe that that will also add to the data base.

Mr. SHAYS. Could the other three panelists respond?

Mr. DWYER. School psychologists have been involved in working with some of the work that Jim is doing. NASP is continuing to explore relationships with researchers in terms of what kinds of things we can do cooperatively. NASP has agreed to continue to disseminate the information. In other words, as soon as the information gets out, we want to make sure that our members and parents and others receive that information as quickly as possible.

Dr. ZARIN. Can I add something to that?

Mr. SHAYS. Yes.

Dr. ZARIN. I think that's a very critical point. Both the American Academy of Child and Adolescent Psychiatry and the American Psychiatric Association are very interested in disseminating re-

search data to clinicians. We already know, based on the research data we have now, as you've heard, that there is a gap between what we would define as optimal treatment based on the information we have now and the type of treatment that many children are getting.

So even before we get the results from the study that Dr. Jensen was describing, I think there is still a lot of work in improving the types of treatment—evaluation and treatment that children are getting.

Mr. SHAYS. Can anyone else respond to this comment? Dr. Swanson.

Ms. CONRAD. I agree.

Mr. SHAYS. You're not representing an organization as such in your testimony.

Ms. CONRAD. No.

Mr. SWANSON. Kevin mentioned that school psychologists are—that we're working with school psychologists. The program that I offer and direct in Irvine is a school-based program. And it's intended to primarily provide nonpharmacological treatments first, behavioral treatments in a laboratory school; and then, if needed, add medication, second. And in our school program, with intensive intervention, only about 40 percent of the children who have the diagnosis are actually treated with medication in our school setting. And that's because of the intensity of the behavioral intervention that we can bring to bear in a laboratory school setting.

Mr. SHAYS. Can you give me that statistic again?

Mr. SWANSON. Pardon?

Mr. SHAYS. Would you repeat that last statistic again?

Mr. SWANSON. In our school setting, there's a laboratory school with very intensive behavioral treatment.

Mr. SHAYS. Right.

Mr. SWANSON. And we do that first before we add medication. We diagnose ADHD, put children in a laboratory school on a university campus, and we deliver behavioral treatment with focussing on five specific behaviors: getting started, staying on task, interacting with peers, completing work, finishing and shifting to a new activity every classroom period. We use a contingency management program as the basic principles and techniques of behavior modification to try to focus on those behaviors.

And we don't think that this is something that would fly out there in the regular clinical treatment maybe as what you're describing. But this is sort of a test to see what we can do.

Mr. SHAYS. And what is the statistic showing?

Mr. SWANSON. Well, this is actually a clinical program that's not evaluated with rigorous research. But it's just our strategy of intervening with children in a clinical setting.

Mr. SHAYS. Right. But are you keeping statistics on the success of it?

Mr. SWANSON. We have since 1983. We just have testimony rather than research. That's why the MTA study is so important. Because it's using the rigor of randomization to conditions and all of the other rigor of a clinical trial to evaluate the impact of this type of treatment.

Mr. SHAYS. I'm sorry. I'm unclear. Because my next question to any of the panels here was going to be, did we fail to bring forward someone to this committee who would have sat before us as a witness and said, under oath and with all the conviction they had, that they believed that treatment should not involve any medical application?

Dr. ZARIN. Should never involved medical?

Mr. SHAYS. Exactly. Is there such a person out there that's in the field that would say that?

Dr. ZARIN. I mean, there are, for example, members of Scientology who would say——

Mr. SHAYS. No, I'm just——

Dr. ZARIN. I mean, if you're asking if there are people who——

Mr. SHAYS. People who are your peers, there is no one out there that should have been at the table that would have said to us, you don't need to——

Dr. ZARIN. Not that I can think of, no.

Mr. SHAYS. I just wanted to ask. But you are——

Mr. SWANSON. I think I'm the extreme. You can ask Dr. Jensen. Maybe he would like to comment on that, because I'm sure he wouldn't agree with me that only 40 percent of the children should be treated with medication. I didn't say that. I said that's what we do in our clinical program. But I'm pretty extreme in that regard.

Mr. SHAYS. Well, it's interesting work. I'm fascinated with the protocol of what you're allowed to do with children. In the process of trying to understand for the future, what are you allowed to do with young children, given that if you don't treat them and you should, then what responsibilities do you have here?

Mr. DWYER. It's a very difficult and perplexing problem to do field research, if you wish to do research where you don't treat somebody that may need treatment. And the other point is, too, that we in the field, we in the trenches, the teachers, behavioral specialists, school psychologists and others, we want to get effective treatments as quickly as we can, because we know what happens if you don't treat these children. They have a very high arrest rate, and it's a serious problem. I mean, the outcomes are really not good without treatment.

So we want to provide treatment early on. So some of the things that Dr. Swanson has talked about, I have put into practice as a school psychologist, as other psychologists have. And we have, by the way a book of examples which—I've given the committee. And it has several examples of things that are implemented in the trenches, so to speak. And I'm sure the behavioral specialists has done this, as well. And some of these programs do work, even in the field.

The point is that you have to have somebody manage it. There has to be somebody that's really going to follow through. And teachers sometimes need paraprofessionals to give them the kind of support that they need to make it happen, because they can't teach 30 kids and also do reinforcements and behavioral management on a contingency schedule. So we really need those kind of supports.

When we have those, we seem to have very good results.

Mr. SHAYS. It's interesting. When you have those kind of supports, you also have members of the community who say, when I was in school, we didn't have all the support staff, and we turned out OK.

Mr. DWYER. When we were in school, you and I, we didn't notice the fact——

Mr. SHAYS. How have you assessed my age?

Mr. DWYER. You're much younger than I am.

Mr. SHAYS. I am 50 years old. I have less hair than you and you're very fine to put me in the same age as you.

Mr. DWYER. We're in the group.

Mr. SHAYS. You know how I always age is I just ask someone when they graduated from high school. I graduated in 1964. When did you graduate?

Mr. DWYER. I graduated before you did. When I went to school, the kids with these problems who didn't graduate, the kids who didn't leave eighth grade, we don't know what happened to them, we didn't see them afterwards.

Mr. SHAYS. I hear you.

Mr. DWYER. Graduation rates in 1950 from high school were significantly lower than what they are today, significantly. We're talking 50–60 percent among certain racial groups in this country that didn't graduate from high school.

We don't have to presume that all of those youngsters had attention deficit disorder, but they certainly had problems.

Mr. SHAYS. Let me do this. You've been a wonderful panel. Is there any last comment you want to make? I'm going to invite anyone from the second or first panel to come and make a comment or two, if they want, within reason.

Ms. CONRAD. I'd just like to reiterate the need to, as he was saying, for early intervention in the early elementary grades, because, like in our district, you have a counselor in the building once a week, a school psychologist in the building once a week. There is no way for the teachers to deal—there really isn't for everything that they're dealing with today.

Mr. SHAYS. Well, you've been a wonderful panel. And I thank you very much. Dr. Jensen, I know you might want to respond. Anyone else who is ready, if you'll come and respond, I'd be happy to have you do that. Thank you all. And, Dr. Jensen, Mr. Morris, please feel free to come up.

Mr. DWYER. Thank you for doing what you're doing.

Mr. SHAYS. Well, thank you for saying that. I was beginning to be concerned that you might think my attention was drifting here.

Dr. ZARIN. Could I make one last comment?

Mr. SHAYS. You sure may.

Dr. ZARIN. I would like to thank you on behalf of the organizations that I represent for your support for parenting. I think that's certainly an important issue in this particular diagnosis, as well as other diagnosis.

Mr. SHAYS. You're welcome.

Dr. JENSEN. Mr. Chairman, perhaps I could preface my final comments by the statement, when you and I were in school—without giving away my age—I would say the issue of "do no harm", both in research and clinical settings, is paramount to the thinking

in medical practice. So, for example, the study that's been alluded to, it would be inappropriate to send a child out to no care or to have a child on a placebo or something over a long period of time in the course of development.

So, for example, in the six-site study, the children are provided any of the three state-of-the-art treatments, which are being tested against each other. This behavioral treatment, combination or medication, versus what's available in the community. The sad part of that is, of course, is that there is not always sufficient treatments available in the community. And that touches on the issue of parity that Dr. Zarin mentioned.

The second point I would make is—and it picks up on Dr. Zarin's comments—while there is a consensus of clinical wisdom that it's nice to provide the child with the full range of treatments. And that's this idea of medication plus behavioral treatments. In practice, many of us do begin, as Dr. Dwyer alluded to, that is, we begin with the psychosocial intervention and we find out how far that takes us. And then we add medication, depending on the child's response in the home and school setting. So, often it's a very thoughtful, "feathered" approach as we feather in one treatment on the next.

Mr. SHAYS. Thank you. Ms. Richard, do you have a comment?

Ms. RICHARD. I would just like to reiterate my thanks to the committee. When I started out 10 years ago with my children, I felt very much alone. And I am extremely grateful today for the fine experts from the Department of Education, from Congress, from the National Institute of Mental Health, who are combining their tremendous resources to help parents like me.

Mr. SHAYS. Thank you. Mr. Morris.

Mr. MORRIS. Thank you. Just very briefly. With respect to trying environmental or behavioral——

Mr. SHAYS. Why do I want to laugh and smile when you come up and talk? What is there about you?

Mr. MORRIS. I don't know.

Mr. SHAYS. I don't know, either.

Mr. MORRIS. Anyway, regarding the behavioral or environmental strategies first, certainly that's the way we all intuitively want to look at it. We want to, intuitively as parents, we want to discipline our kids and we want to show them the right way.

And from the perspective of ADDA as an organization that hears from people who are struggling as adults and struggling as parents all of the time, we would advocate, based on current findings out there, that if the child or the adult has gone through sufficient diagnostic procedures where the diagnosis is pretty much assured by experts out there, that medical treatment be provided. And that particularly in an insurance kind of an environment, that there shouldn't be impediments to that treatment.

I mean, to use that eyeglass analogy once again, would you withhold glasses from a child who was found to have a vision problem by an ophthalmologist? We're just going to try to make him see a little harder first. Would you withhold glasses from an adult who had a vision problem that's about to get into a car, you know, and head for the Beltway? Just drive a little more carefully.

We firmly believe that use of medicine should be preceded by diligent medical diagnosis from a variety of areas. But once that diagnosis has been made, we don't advocate holding back the medicine.

Mr. SHAYS. The danger of using concepts like the glasses are that you could use it the other way and say, the person is seeing all right, but there are other factors for why they're not behaving well. Giving them a new prescription when they can already see can be a problem, too.

Mr. MORRIS. Indeed.

Mr. SHAYS. You all have been great. You've been very patient with someone who is trying to get a handle on this subject. I thank you all very much. We would also like to thank Chris Allred of the majority staff and Cheryl Phelps of the minority staff, as well as our court reporter, Maryann Kohler, for her participation. With that, we call this hearing to a close.

[Whereupon, at 5:10 p.m., the subcommittee was adjourned.]

[Additional information submitted for the hearing record follows:]

OPENING STATEMENT OF REP. ED TOWNS
BEFORE THE SUBCOMMITTEE ON
HUMAN RESOURCES AND INTERGOVERNMENTAL RELATIONS

"OVERSIGHT OF THE DEPARTMENTS OF EDUCATION AND
NATIONAL INSTITUTE OF MENTAL HEALTH:
Current Approaches to Attention Deficit / Hyperactivity Disorders"
July 16, 1996

MR. CHAIRMAN, I APPRECIATE THIS OPPORTUNITY YOU HAVE PROVIDED US TO EXAMINE THE EFFECTIVENESS OF THE DEPARTMENT OF EDUCATION AND NATIONAL INSTITUTE OF MENTAL HEALTH POLICIES REGARDING ATTENTION DEFICIT / HYPERACTIVITY DISORDER.

FOR 3 TO 5 PERCENT OF OUR SCHOOL-AGED CHILDREN, EDUCATIONAL ACHIEVEMENT IS ESPECIALLY DIFFICULT BECAUSE OF A NEUROBIOLOGICAL CONDITION THAT INTERFERES WITH THE CHILD'S ABILITY TO LEARN AND TO BE A PRODUCTIVE MEMBER OF A CLASSROOM. NOW IT APPEARS THAT THIS SAME DISORDER MAY BE INTERFERRING WITH THE ABILITY OF A NUMBER OF

UNDIAGNOSED ADULTS TO FUNCTION AS PRODUCTIVE MEMBERS OF SOCIETY AS A WHOLE.

MR. CHAIRMAN, UNDER FEDERAL LAW, THE EDUCATIONAL NEEDS OF ATTENTION DEFICIT / HYPERACTIVITY DISORDER-DIAGNOSED CHILDREN MUST BE MET WITHIN THE PUBLIC SCHOOL SYSTEM. HOWEVER, SEVERAL VARIABLES CONTRIBUTE TO THE DIFFICULTIES EDUCATORS, MENTAL HEALTH CARE PROFESSIONALS, AND POLICY MAKERS FACE IN IDENTIFYING APPROPRIATE SERVICES AND CARE FOR THE ESTIMATED 1.46 TO 2.44 MILLION AMERICAN CHILDREN WITH THIS DISABILITY.

THERE ARE ALSO DIFFERENCES OF OPINION BETWEEN FEDERAL AGENCIES, ADVOCACY GROUPS, AND HEALTH PROFESSIONALS REGARDING APPROPRIATE DIAGNOSIS AND MANAGEMENT OF AD/HD.

FOR EXAMPLE, WHILE THE DEPARTMENT OF EDUCATION ESTIMATES THAT 3 TO 5 PERCENT OF U.S. SCHOOL-CHILDREN HAVE AD/HD, ONE ADVOCACY ORGANIZATION APPEARING BEFORE THE SUBCOMMITTEE TODAY BELIEVES THAT AS MANY AS FIFTY PERCENT OF CHILDREN WITH AD/HD ARE NOT PROPERLY DIAGNOSED.

IN ADDITION, ACCORDING TO THE DRUG ENFORCEMENT ADMINISTRATION, THE UNITED STATES MANUFACTURES AND CONSUMES MORE THAN 80 PERCENT OF THE TOTAL WORLD SUPPLY OF METHYLPHENIDATE ("MEH-THILL-FEH-NEH-DATE"), THE DRUG COMMONLY USED TO TREAT AD/HD -- FIVE TIMES MORE THAN THE REST OF THE WORLD COMBINED. QUESTIONS HAVE BEEN RAISED THAT THIS PSYCHO-STIMULANT, BETTER KNOWN BY ITS BRAND NAME, RITALIN, IS OVER-PRESCRIBED, AND THAT THE DRUG HAS A POTENTIAL FOR RECREATIONAL ABUSE.

CONCERNS HAVE ALSO BEEN RAISED THAT A NUMBER OF THE U.S. CHILDREN TREATED WITH METHYLPHENIDATE FOR AD/HD, OFTEN DO NOT BENEFIT FROM THE OTHER SERVICES SUCH AS BEHAVIORAL MODIFICATION TRAINING AND PSYCHOTHERAPY AS RECOMMENDED IN TREATMENT GUIDELINES.

MR. CHAIRMAN, I BELIEVE THAT THIS HEARING WILL SERVE TO CLARIFY THESE ISSUES AND PROMOTE OUR UNDERSTANDING OF THEIR IMPLICATIONS FOR FEDERAL EDUCATION AND HEALTH POLICIES.

TOWARD THIS END, I WELCOME TODAY'S WITNESS AND THANK THEM FOR THE TIME AND EFFORT THEY HAVE SPENT PREPARING FOR THIS HEARING.

STATEMENT BY
THE AMERICAN ACADEMY OF PEDIATRICS
FOR THE
HOUSE SUBCOMMITTEE ON HUMAN RESOURCES AND INTERGOVERNMENTAL AFFAIRS
SUBMITTED JULY 31, 1996
FOR THE HEARING ON
JULY 16, 1996

The American Academy of Pediatrics is pleased for the opportunity to present a statement for the record to the House Subcommittee on Human Resources and Intergovernmental Affairs regarding attention deficit/hyperactivity disorder (ADHD). The Academy -- an organization of 50,000 pediatricians dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults -- has been a visible and active advocate for children with mental and behavioral issues for decades.

Assessment of a child's physical, mental and behavior function is an every day activity for pediatricians. It is timely, even ironic, that the Congress chose to begin exploring issues surrounding attention deficit disorder the same week that the Academy held a meeting to begin developing adequate tools for primary care clinician to make an accurate diagnosis of ADHD.

Though children with attentional difficulties have been described since the turn of the century, this disorder has been the subject of intensifying interest in both the medical and public arenas. Dramatically increased identification, diagnosis, medical treatment and publicity over the last 25 years has made ADHD a household term.

ATTENTION DEFICIT/HYPERACTIVITY DISORDER

Children with ADHD demonstrate a persistent pattern of inattention or hyperactivity and impulsivity that is more frequent and severe than that observed in other children at a similar level of development.[1] The primary symptoms of these disorders occur along a continuum of severity and include:

-- difficulties with attention, including easy distractibility;
-- difficulty with impulse control;
-- problems with maintaining appropriate task-related activities;
-- disorders of executive function, including planning and organization of cognitive tasks;
-- difficulty recognizing and responding to social cues;
-- difficulty attending to directions;

---

[1]American Academy of Pediatrics, Committee on Children with Disabilities. AAP defines attention-deficit hyperactivity disorders. *AAP News*. 1991; 7:12-13.

-- low frustration tolerance; and
-- overactivity

DIAGNOSIS AND EVALUATION

ADHD is medically diagnosable, however, there is the potential for both under and overdiagnosis. A key component to reliable, accurate diagnosis is the availability of adequate tools with which to make the evaluation.

As noted above, the AAP has begun a 2-3 year project to develop practice parameters/guidelines on the diagnosis and management of ADHD in pediatric practice. Two separate guidelines will be developed. One on diagnosis/evaluation and one on treatment. Recognizing there is a substantial amount of variation in current clinical practices, the AAP was encouraged by its membership to provide parameters on ADHD that could potentially narrow the practice variation by providing new, evidence-based information and recommendations. The increase in information regarding diagnosis, epidemiology, comorbidity, treatment and long-term outcomes could be used to assist pediatricians in clinical decision-making in diagnosis and management of patients with ADHD.

In addition to the AAP's efforts to develop guidelines, multidisciplinary teams of pediatricians, psychiatrists, and psychologists have developed The Classification of Child and Adolescent Mental Diagnoses in Primary Care Diagnostic and Statistical Manual- Primary Care (DSM-PC). This manual, which expanded on the Diagnostic and Statistical Manual-IV, describes and classifies a broader spectrum of child and adolescent mental health diagnoses and conditions. ADHD is one of many disorders included in the DSM-PC. This manual will more specifically define problems and normal variation levels. These distinctions, along the continuum of severity assist primary health care providers in diagnosing ADHD by addressing the "gray areas' of symptomatology. The manual will be available in October 1996.

Although attentional disorders may occur alone, they are more commonly occur with other conditions such as learning disabilities or conduct disorder.

Many educators and physicians do not realize that a differential diagnosis exists for these behaviors much as for any other complex symptoms. To establish an accurate diagnosis, information must be obtained concerning factors such as:

-- behavioral information from parents and teachers;
-- the child's birth, developmental, family, medical, psychosocial, and scholastic histories;
-- sensory screening (ie, vision and hearing); and
-- physical, neurologic and neuromaturational examinations.

An appropriate diagnostic evaluation is essential before a child begins any drug therapy for learning or behavior problems, both to establish a diagnosis and to identity commonly associated disorders that may require specific intervention. Such an evaluation often requires

that the child be seen by other health professionals, such as psychologists, speech pathologists, and educational diagnosticians, in severe and complicated cases by child psychiatrists.

INDICATIONS AND THE USE OF MEDICATION

The use of drug therapy in the management of the child with ADHD does not differ appreciably from the drug therapy in other treatable illnesses. In both instances, prescription drugs should be prescribed only by appropriately licensed physicians. Although screening of patients may frequently be done by other disciplines, the ultimate selection of patients to be treated remains the responsibility of the prescribing physician.

The AAP has developed several principles related to medication for ADHD:

- Drug therapy should not be considered a panacea or cure-all. The decision to use medication must always consider the overall needs of the child and family.

- Medication for children with attentional disorders should rarely be used as a sole treatment. Pediatricians must work in concert with parents, principals, teachers, special educators, and school nurses to combine drug therapy with appropriate management of the child's environment and curriculum.

- Medication should not be used without clear evidence that a child's attentional difficulties significantly affect school performance, cause difficulties with social adjustment, or are associated with a significant behavioral disorder.

- Medication should not be continued if clear-cut benefits are not observed.

The Academy commends the Congress for its desire to learn more about attention deficit/hyperactivity disorder. Research into ADHD is needed to better understand the implications of this condition in the continuum of development from childhood through adulthood. Unquestionably, a thoughtful and comprehensive review of ADHD is the most effective and responsible approach to addressing potential fiscal and policy issues related to behavioral disorders.

The Academy offers the expertise of its membership to the Congress on this, and other important issues.

[NOTE.—The following materials can be found in subcommittee files.]

Attachments

Attachment 1 - DoEd publication, "Attention Deficit Disorder: Adding Up the Facts"

Attachment 2 - CH.A.D.D. publication, "The Disability Named ADD, An Overview of Attention Deficit Disorders"

Attachment 3 - Newsweek cover story, "Ritalin, Are we Over medicating our Kids?"

Attachment 4 - CH.A.D.D. publication, "Medical Management of Attention Deficit Disorders"

Attachment 5 - article by Dr. Jensen and others, "NIMH Collaborative Multisite Multimodal Treatment Study of Children with ADHD: I. Background and Rationale

Attachment 6 - DoEd publication, "Attention Deficit Disorder: What Teachers Should Know"

Attachment 7 - New York Times article, "Boom in Ritalin Sales Raises Ethical Issues"

Attachment 8 - Washington Post article, "Attention Deficit Disorder: Do Millions of American Really Have It?"

Attachment 9 - publications "The Child and Adolescent Psychiatrist," and "What is Psychotherapy for Children and Adults?"

○