THE TASK FORCE TO
STUDY THE USE OF
METHYLPHENIDATE & OTHER DRUGS
ON SCHOOL CHILDREN
REPORT

March 1999
**TABLE OF CONTENTS**

Letter from Task Force Chair................................................................. 1
Dedication................................................................................................. 2
Task Force Members .............................................................................. 3
Task Force Consultants and Professional Staff........................................ 4
Executive Summary................................................................................ 5
Findings .................................................................................................... 5-10
Recommendations................................................................................... 11-14
A Review of Data on ADHD Treatment.................................................... 15-21
References.............................................................................................. 22-23
Appendixes:
A) Diagnostic and Methylphenidate Information................................. 23-25
B) Summary of Public Testimony......................................................... 26-27
C) ADHD Medication Prevalence Survey........................................... 28-33
D) The Maryland Interdisciplinary Conference on ADHD................ 34-35
E) Summary of Report of Findings on Focus Group Meetings
   Lessons from Listening to Parents of ADHD Children.................... 36-45
F) Survey of Maryland Local School Systems on ADHD................ 46-48
G) Selected Resources........................................................................ 49-56
March 1999

Governor Parris N. Glendening 
Thomas V. Mike Miller, Jr., Senate President 
Casper R. Taylor, Jr., House Speaker 
State House 
Annapolis, MD 21401-1991

It is a privilege to submit to you and the Maryland General Assembly the report of the Task Force to Study the Uses of Methylphenidate and Other Drugs on School Children which was established by House Bill 971. This report is the culmination of countless hours of work on the part of Task Force members and staff from the Maryland Department of Health and Mental Hygiene and the Maryland State Department of Education.

Information gathered by the Task Force indicates that Maryland is comparable to other areas of the country in the rate of medication treatment for Attention Deficit Hyperactivity Disorder (ADHD). This should not necessarily be interpreted as a good or bad sign. A large number of variables (e.g., age, gender, geographical location and ethnicity) have an impact on the treatment of ADHD and are addressed in detail in the report.

Although there seems to be a great deal of controversy concerning the use of stimulant medication, the current literature, using well-controlled studies, indicates that at this time, medication in conjunction with other support services offers the best therapy for these children and youth.

We believe that the attached report and its appendixes fulfill the directive of the Task Force.

Sincerely,

Sidney B. Seidman, M.D.
Chair
Dedication

The Task Force members who developed this report clearly recognize that the issues contained in these pages originate and have their primary impact on the lives of families. We want from the outset to acknowledge the many stresses, frustrations, and burdens that family members experience in parenting a child with Attention Deficit Hyperactivity Disorder (ADHD). Many parents and family members consulted in Task Force sponsored focus groups spoke to the seemingly unrelenting impact of these problems on every aspect of their daily life. Some recognize that their struggles are part of a larger public health and educational problem which requires thoughtful and creative solutions. As one family member noted: "... it seems to me that what we have here is an epidemic and very widespread, and it needs to gain local, national attention . . . ."

Often confronted with painfully difficult decisions, families report an unfortunate feeling of being blamed for their child's condition in not too subtle ways by school and health professionals alike, as well as by extended family members and the community at large. Caught up in the social controversy surrounding the use of medication, the very same issue which led to the creation of this Task Force, most parents indicate that medication has helped their child, but they wish that its use had not been necessary. This ambivalence and the dilemma posed by medication is crucial to many of the issues explored in this report. In the succinct words of one parent, "I don't want him on medicine really, but it helps him." Beyond the questions of medication, parents are quick to point out the need for coordinated and compassionate educational, treatment, and supportive services. They also emphasize the real importance of accurate information and how it is communicated.

In the face of these problems, some families have become a great source of strength and advocacy on behalf of their children. Often called upon to be extremely vigilant in monitoring their child's behavior, parents also recognize the burdens that ADHD presents for educators and health professionals. Families and their perspectives represent a significant resource in moving towards a more effective comprehensive solution to the problems of ADHD. When pursued alone, even powerful family advocacy can be burdensome for the family; it needs to be supported and responded to by school and health care systems. As a result, in the spirit of a collaborative venture, we dedicate this report to Maryland's children and youth with ADHD and to their families, in the hope that it will engender even bolder action in Maryland for implementing the recommendations of this report and for developing improved services for ADHD.
TASK FORCE to STUDY the USES of METHYLPHENIDATE and OTHER DRUGS ON SCHOOL CHILDREN

TASK FORCE MEMBERS

Sidney B. Seidman, M.D. - CHAIR
State Board of Physician Quality Assurance
Pediatrician

Harolyn Belcher, M.D.
Kennedy Krieger
Developmental Pediatrician

Gail I. Dunlap, M.Ed.
Harford County Schools
Special Educator; Assistant Principal

John Grant, M.D.
Kent County Health Department
Health Officer

The Honorable Paula C. Hollinger
Maryland State Senate
Senator

W. David Humbert, M.A.
Carroll County Public Schools
School Psychologist

Linda Jacobs, Ed.D.
Director of The Harbour School
Special Educator

Theo Lemaire, Ph.D.
Private Practice
Clinical Psychologist

Pamela Lewis, R.N.
Parent of child with ADHD
School Nurse

Patricia Michel, C.P.A., M.B.A.
Coordinator of CHADD
(Baltimore County)

The Honorable Dan Morheim
Maryland House of Delegates
Delegate

Pauline B. Prince, Ph.D.
School Psychologist
Parent of a Child with ADHD

Geneva Rawls, M.Ed.
Maryland State Teachers Association
Special Educator

Mark Riddle, M.D.
Johns Hopkins Hospital
Child Psychiatrist

Mary Healy Shiner, R.N.,M.S.
Baltimore County Schools
School Nurse

Milton Shore, Ph.D.
Board of Psychology
Psychologist

Larry B. Silver, M.D.
Georgetown University Medical Center
Child and Adolescent Psychiatrist

Ken Tellerman, M.D.
American Academy of Pediatrics
General/Behavioral Pediatrician

Julie Magno Zito, Ph.D.
University of Maryland
Associate Professor, Pharmacy/Med
TASK FORCE CONSULTANTS

David Bromberg, M.D.
Private Practice, Pediatrician

William Flook, Ph.D
School Psychologist, Anne Arundel County Public Schools

Linda Grossman, M.D.
Private Practice, Developmental Pediatrician

Rick Ostrander, Ed.D.
Private Practice, Psychologist

Polly Roberts, M.D.
Private Practice, Pediatrician

Daniel Safer, M.D.
Private Practice, Child Psychiatrist

TASK FORCE PROFESSIONAL STAFF

Cheryl Duncan, M.D.
Director of Assurance and Medical Policy
Department of Health and Mental Hygiene

David Holdefer, M.A., NCSP
Specialist, Psychological Services
Maryland State Department of Education

Donna Mazyck, R.N., B.S.N., C.S.N.
Health Specialist
Maryland State Department of Education

Thomas Merrick, M.A.
Grants Administrator
Child and Adolescent Services
Department of Health and Mental Hygiene

Pamela Putman, R.N., M.P.H.
School Nurse Consultant
Department of Health and Mental Hygiene

Vicki Taliaferro, R.N., B.S.N., C.S.N.
Health Specialist
Maryland State Department of Education
Executive Summary
of the
Task Force to Study the Uses
of Methylphenidate
and Other Drugs On
Schoolchildren
Executive Summary
of the
Task Force to Study the Uses of Methylphenidate
and Other Drugs on School Children

The 1997 Maryland General Assembly passed House Bill 971 establishing the “Task Force to Study the Uses of Methylphenidate and Other Drugs on School Children”. Its specific charge was to: determine the prevalence of the use of methylphenidate among school-age children and youth in the state; determine the extent to which treatments for attention deficit hyperactivity disorder other than methylphenidate are generally available or in use; and determine who prescribes methylphenidate to school age children and why. In meeting the charge of the legislature, the Task Force undertook the following activities:

- reviewed the relevant literature and current research including professional society practice guidelines and surveys
- conducted a statewide medication prevalence survey completed by public school nurses
- held parent focus groups
- surveyed school systems regarding policies pertaining to students with attention deficit hyperactivity disorder
- held public hearings
- consulted with various professionals on alternative treatment approaches
- planned and coordinated a state-wide interdisciplinary conference on ADHD

TASK FORCE FINDINGS

Definition of ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a disorder characterized by behavior and attention difficulties which are exhibited in multiple settings, but most prominently in the classroom. It begins in childhood and is identified by specific attention, hyperactivity, and impulsiveness criteria found in the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM IV, 1994). The disorder is subclassified as follows: predominantly inattentive type, hyperactive-impulsive type, and combined type. To be classified as ADHD, the child or youth must exhibit the requisite number of descriptors from the DSM IV, present clear evidence of a significant impairment in social and academic functioning, and experience these problems for at least six months in duration.
Prevalence of ADHD

The prevalence of ADHD in children and youth has been reported in studies to be varied with an average of five percent to eight percent. Recent prevalence rates have been higher than previous ones because the diagnostic category has become more inclusive over the last two decades. The prevalence of ADHD varies prominently with age and gender. The peak age for the expression of the disorder is ages eight-eleven years, and the rate for youths ages seven-eleven is over twice that for youths ages twelve-sixteen. Boys outnumber girls by at least two to one. The diagnostic rate also varies depending on the number of sources of informational input. That is, when multiple informants --parent, teacher, and physician --all agree that the child’s characteristic pattern fits within the ADHD category, the recorded diagnostic rate is far less than when only one observer describes the pattern.

Evaluation of ADHD

• Every child and youth exhibiting the characteristics of ADHD deserves an adequate professional assessment.

• The evaluation should include relevant input from the child’s teacher(s) and educational support staff, his/her parents or guardians, the child, and one or more medical/mental health professional.

• Parent involvement is vital to convey the developmental history, details of medical illnesses and treatment, any prior educational or mental health interventions, and to describe the child’s social and behavior pattern in relation to the family’s social context.

• The educational assessment should include a comprehensive report on the child’s academic level and classroom adjustment. Whenever possible, it should also include information on the child’s adjustment during previous school years so as to identify the presence or absence of a persistent behavioral or academic pattern.
Treatment of ADHD

General Approaches

- Optimal therapeutic intervention for ADHD should provide continuous care and monitoring, and cover all aspects of the child’s handicap/maladjustment.

- Coordination among parents, educators and involved medical/mental health professionals optimizes treatment outcome.

- Motivated and productive parent involvement is vital to support the child’s academic endeavors. This is crucial should teacher-parent coordinated behavior management be selected as a treatment for ADHD.

- Non-pharmacologic interventions (for example, tutoring, educational counseling, a classroom behavior management, and parent behavior management training) play a major role in treating the educational, psychological, and social difficulties experienced by children and youth with ADHD.

- Guidelines and consensus statements concerning the diagnosis and treatment of children and youth with ADHD from the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, the National Institute of Health, the National Association of School Psychologists, and/or the American Medical Association’s Council on Scientific Affairs should be readily available and utilized in quality assessment reviews of Maryland child health and school health programs.

- Aside from parent-focused and classroom-based behavior/educational therapies and stimulant treatment, there is relatively little in scientific literature at this time to support the effectiveness of other therapies for ADHD. Parents are advised to consult with one or more experts before engaging in novel, alternative approaches to deal with their child’s difficulties.

Treatment with stimulants and other medications

Stimulant medication is a major medical treatment modality for children and youth with ADHD. Methylphenidate (Ritalin®) accounts for 85% to 90% of the stimulants prescribed for this purpose, but other stimulants, such as Adderal® and dextroamphetamine, are being increasingly prescribed. In clinical trials, stimulant treatment measurably benefits 75% or more of children and youth with ADHD by lessening their hyperactivity, improving attention, improving classroom productivity, lessening those conduct problems related to undue restlessness, and improving fine motor coordination—if it is impaired. Stimulants continue to have their symptomatic benefits as long as the difficulties that characterize ADHD remain. A large, six site, National Institute of Health sponsored comparative treatment study reported in 1998 that 14 months of systematic stimulant treatment was the single most beneficial treatment for ADHD. Nonetheless, these medications by themselves do not measurably alter the academic achievement levels and the rate of delinquency when these are assessed during controlled long term outcome studies.
The rate of medication treatment for ADHD has risen steadily in the United States since the late 1960's from estimates of 300,000 youths in the early 1970's to 1.5 million (for methylphenidate) in 1995. The rate of increase during the 1990's has been somewhat greater than in the past. Between 1990 and 1995, a number of regional data-based studies revealed a 2.5 fold average increase. A conservative estimate in 1995 was that 2.8% of United States school-aged youth (ages 5-18) were receiving methylphenidate treatment. Figures from around the United States in 1996 and 1997 indicate that the steady increase for stimulant treatment has continued.

In response to Maryland House Bill 971, the rate of medication treatment for ADHD for Maryland public school students was tabulated by school nurses in April, 1998. The recording included all students who were administered a medication for ADHD during school hours. Among the 816,465 students enrolled in 1998, 23,771 (2.91%) received medication for ADHD during the school day. When split by type of medication, 20,050 students (2.46%) received methylphenidate and 3,721 (0.46%) received other medications for ADHD.

To assess the limitations of the school survey, an estimate was made of how many students received medication for ADHD only-at-home and not in school. The only-at-home medication rate for ADHD was estimated at 20% of the total number of children on medication for ADHD based on surveys in Baltimore County in the 1990's and on 1997 surveys in a pediatric clinic and among members of a consumer advocacy group. Combining the school day administration rate with the estimate of the only-at-home administration rate yields a corrected total figure of 3.65% for public school students (ages 5-18) administered any medication for ADHD and a 3.08% total for methylphenidate. The rate may be slightly lower because some children and youth receive more than one medication for ADHD.

As with most medical treatments, the prevalence data for medication treatments for ADHD show considerable variation depending on geographic locale, age, gender, ethnicity, and socioeconomic status, as well as physician specialty and health care system. Whereas the total school administered methylphenidate prevalence was 2.46%, the elementary school rate was 3.11% which was nearly equaled by the middle school rate of 2.90%. High school students had a methylphenidate prevalence of 0.87%. Students receiving special education services had a methylphenidate prevalence of 8.7%. It is of particular note that 12.6% (103,141/816,465) of all Maryland public school students were receiving special education services in 1998 and that 45% (8,971/20,050) of all the public school students in Maryland receiving methylphenidate were in special education. The Maryland survey also confirms numerous previous reports that non-Caucasian students have a substantially lower methylphenidate rate than their Caucasian counterparts.
Medication treatment rates for ADHD in Maryland in 1998 can be compared in a general way to those in other locales of the United States. The Maryland school survey rates for methylphenidate treatment are below those reported in a large school district in Wisconsin in 1996, a 1997 North Carolina single school district rate, and a 1995-1996 survey of two Virginia school districts, but they appear to be above a 1994-1995 school district survey rate in a rural Tennessee county. The only state by state methylphenidate comparison available measured wholesale shipments of the drug in kilograms to each state's retail registrants in the United States. In 1994, Maryland had the fourth lowest shipment rate (per 100,000 population) among the 50 states according to recently released Drug Enforcement Agency figures. In a two state comparison of methylphenidate treatment rates by Medicaid enrollees under age 20, Maryland had a consistently lower rate than Ohio from 1990 to 1994 (the last year of comparative data). Because some of the earlier described rates are for different years and somewhat different populations, comparing the results of one with another should be viewed with caution. Second, the methylphenidate state by state shipment rate is a very crude measure and doesn't necessarily reflect comparative treatment rates for children and youth prescribed that drug.

In the 1998 Maryland school survey, 59% of the student's prescriptions for methylphenidate were written by pediatricians, 16% by family practitioners, 11% by psychiatrists, and 2% by nurse practitioners. The percentage of primary care physicians prescribing stimulants for ADHD in Maryland matches the number reported in other locales of the United States.
The Task Force conducted a survey of Maryland public school systems addressing school guidelines and policies for the management of children and youth with ADHD. There are 24 local school systems, and apparently 24 different ways of providing school services to children and youth with ADHD in Maryland. Some systems have developed comprehensive local policy and procedural guidelines specifically for these students, but most have not.

Most school systems cited general procedural guidelines that are employed with all students with disabilities (special education or “Section 504”), but did not cite specific procedures for students with ADHD. Many systems were not clear regarding how to apply special education procedures to children and youth with ADHD.

- Fifty percent of the school systems cited a specific written definition of ADHD.
- Four out of the 24 local school systems have an explicit written policy against school personnel recommending medication for ADHD. Ten more systems cited oral or informal policies to this effect, while ten more had no policy at all in this area.
- In most school systems, staff development on ADHD is inconsistently available, or not available to all staff at all levels. Two systems cited a broad range of staff development offerings in this area.
- Few local school systems have implemented any systematic tracking or case monitoring of students with ADHD, and no system has cited the collection of any data on these students across schools and from year to year.

Information from the public hearings and from focus groups indicates that many parents have concerns about the management of their children and youth in local school systems.
Task Force Recommendations
Recommendations

It is proposed that the Maryland State Board of Education require written guidelines in every jurisdiction because school guidelines for the diagnosis and treatment of children and youth with ADHD are incomplete or unwritten in a sizable number to local school systems in Maryland. Carroll County and Baltimore County have comprehensive, well thought out written guidelines; consequently, these two local school systems are recommended for use as models by local school systems not having adequate guidelines. Preferably, the guidelines should be the product of a combined effort by each local school system and department of health.

Recommendations for System Coordination:

1. A school team approach for children and youth with ADHD to aid in the diagnosis, treatment and, if need be, referral to an outside professional.

2. A policy limiting school staff from specifically recommending a medication treatment for ADHD.

3. A policy to specify a minimum degree of parent-school staff communication in cases of children or youth suspected of having ADHD.

4. Policies to formalize with parental consent communication between involved school staff and the treating therapist/physician to provide the outside professional with baseline data on the student’s classroom maladjustment pattern, and, when necessary, follow-up classroom findings to aid in the monitoring of treatment.

5. While many children and youth with ADHD have academic deficits, not all require special educational services or a 504 accommodation plan in school. Many ADHD children and youth can and should be accommodated successfully in a regular education classroom.

6. Not all children and youth with ADHD should be identified as “educationally disabled.” Not all children and youth with ADHD are the same. Careful consideration must be given to the risks and benefits of including borderline cases in an educational ADHD category because this identification may limit the child’s opportunities in the future.

7. Third party payers should be encouraged to reimburse professionals for comprehensive diagnostic assessments and for the multi-modal treatment of ADHD.
Recommendations For The Educational Community

1. Smaller class sizes and support systems that foster flexibility in the management of children and youth with ADHD are needed. Smaller class sizes are particularly needed for the younger age group at a ratio of 1 teacher for every twenty or less children in the kindergarten through second grade group.

2. Expanded teacher's knowledge of ADHD should be encouraged by local school systems.

3. The Maryland State Department of Education should develop a clearinghouse of good educational practices for ADHD for local school systems. For example, all schools should utilize a simple method to monitor the classroom outcome of treatment.

4. Guidelines are needed to clarify the interpretation of regulations based on federal laws, specifically, Individuals with Disability Education Act (IDEA) and Section 504 of the Rehabilitation Act policies and requirements. Decision protocol and organization charts could assist in the appropriate implementation.

5. A mental health professional who is knowledgeable about ADHD and its educational implications should be available in each school system so as to facilitate the recommendations described above.

6. Informed written parental consent is needed during the diagnostic evaluation so that if parent-selected professionals outside the school system are or soon will become involved, they can receive and share with the school staff pertinent information concerning the child.
Recommendations For The Support of Families

1. Parents should be encouraged to advocate for an active role in the evaluation of treatment effectiveness based on community-based assessments. This is a goal that can be fostered by ongoing educational programs to increase parental knowledge of ADHD diagnosis, psycho pharmacologic and non-psycho pharmacologic benefits and risks, and the long-term outcomes of treatment. Similarly, ongoing parental involvement with the educational system may foster a more satisfying classroom experience for teachers and their students.

2. Identify an ADHD resource center to serve parents as well as professionals, educators, and administrators which would accomplish the following functions: raise public knowledge of ADHD, provide current information on ADHD for parents, develop community resources, provide “best practices” information on diagnosis and treatment, provide referral information, and generate research initiatives.

3. Facilitate a shift in emphasis of intervention towards reducing parent burden by increasing access to family and community resources, enhancing system coordination, and helping parents advocate for their child.

4. Establish supportive activities (peer support groups, workshops, advocacy services, community activities for children) for families within the community, school, and treatment settings. The greater availability of these activities will both reduce the stress and frustration of parents, children, and professionals and increase parents’ advocacy skills.

5. Design public awareness campaigns and direct pre-service and in-service presentation to recognize and acknowledge the stress and burden that an ADHD child brings to the family and reduce the tendency to blame parents for their child’s behavior.


7. Sensitivity to the cultural, educational, socioeconomic and individual differences among the families of children and youth with ADHD should be encouraged to facilitate optimal care for all citizens of Maryland.
**Recommendations for the Medical Community**

1. Medical evaluations of children and youth with difficulties in learning should include communication with the child’s educators.

2. Communication between physicians and educators regarding the use of medication for school-age children and youth with ADHD should be improved with emphasis on reporting symptom changes, school performance, and social development. Two excellent examples of a classroom teacher’s behavior rating scale are included in Appendix.

3. Clinicians should be monitoring and tracking children and youth with ADHD in regard to the broad outcomes of treatment including symptom improvement, academic performance, social development, reasons for changes in medication (dose changes, medication additions, discontinuations), and side effect profiles.

4. Professionals involved in the treatment of children and youth with ADHD should assist parents to advocate for comprehensive services for their child.

5. Training for primary medical practitioners regarding ADHD should be expanded and should include information on when to refer the case to a specialist.

**Recommendations for Research / Evaluation**

Few naturalistic outcome studies are currently available, and they provide limited information on the long-term benefits, risks and the cost-effectiveness of treatment. More community-based studies are needed to describe variations in the length of treatment, as well as multi-dimensional (specifically: educational, vocational, social and medical) treatment outcomes.
A Review of Data on ADHD Treatment
Prevalence of the Use of Methylphenidate for Children and Youth with ADHD

There is a great deal of variation in the stimulant treatment of children and youth with ADHD. Rates vary by the age of the child, special education status, gender, comorbid disorders, physician speciality, geographical area, ethnicity, medical payment source, pharmaceutical promotion, media influence, judicial and legislative decisions, year of the survey, and duration of the reporting period (Zito et al, 1998a).

In gathering medication prevalence data, it is necessary to obtain as much of a representative sample as possible or to survey an entire population. Clinic populations have moderate usefulness, but economically advantaged youth treated for a disorder are often selectively seen by private practitioners. Stratified survey data from prescribing physicians is useful if the sample is representative, but most of such samples are relatively small. Data from HMO enrollees is somewhat limited because historically these organizations have catered to employed people and their dependents and to those who have been healthy. Medicaid enrollees include mostly people with low income and from racial minorities.

A total sample from a county or state would be optimal, but this is rarely possible. A school district survey would be comprehensive, but if only public school students were assessed, parochial and private school students, who represent approximately 10% of all students, would not be counted.

The most comprehensive survey was done in Michigan by Rappley et al (1995). She and her colleagues obtained treatment data from the entire state based on a count of triplicate prescriptions for controlled substances. They found that 1.96% of all children and youth ages five-fourteen years were prescribed methylphenidate in February and March of 1992, and children and youth ages five-seventeen years at the rate of 1.6%.

School survey data on the prevalence of stimulant medication treatment for students have been obtained in a number of school districts across the United States since 1971. The three most recent published surveys are presented as follows:

1) The latest published survey from Baltimore County Public Schools indicates that 3.75% of all students were treated with methylphenidate in 1995 (Safer et al, 1996).

2) LeFever et al (1997) reported on a methylphenidate treatment survey covering two school districts in eastern Virginia during the school year 1995-1996. She found that 10.8% of Caucasian and 5.4% of African-American students in the second through fifth grades (ages 7-10) were receiving methylphenidate.

3) In a central Wisconsin school district in January 1996, Musser et al (1998) surveyed all public and parochial school students who received stimulant medication treatment during school hours. She and her group found that 3.7% of the entire student body was receiving stimulant medication.
State to State Comparisons of Methylphenidate Shipments
State to state comparisons of methylphenidate utilization are quite limited. One comparison measures the shipment in kilograms of methylphenidate to each state’s retail registrants. In 1994, according to the latest published reference to these comparative U.S. state figures, Maryland had the fourth lowest rate among the 50 states, receiving 0.83 grams per 100 population (Hancock, 1996).

Age and Gender Variation in Methylphenidate Treatment
Methylphenidate prevalence rates peak at ages eight to eleven and level off markedly after age thirteen. In the Michigan study, the rates for youth age eight-eleven were approximately twice those for youth age twelve to fourteen. The male/female gender ratio for methylphenidate treatment has in recent years been approximately 4:1. (Rappley et al, 1995; Safer et al, 1996; Zito et al, 1998b)

Changes in Prevalence over Time
Population-based assessments of medication treatment have revealed that stimulant treatment for children and youth with ADHD substantially increased since the 1970’s. From 1990 to 1995, the rate of stimulant treatment increased an average of 2.5 fold, such that by 1995, an estimated 1.5 million U.S. school-age youth were receiving methylphenidate treatment for hyperactivity and attention difficulties. (Safer et al, 1996).

Comparative Treatment Rates for ADHD by Medical Speciality
In the U.S., pediatricians consistently treat most youth receiving medication for ADHD. In five separate studies to date, pediatricians treated 40% to 63% of all young patients receiving medication treatment for ADHD. In descending order, the proportion of the total of other medical specialists treating ADHD youth was as follows: family practitioners, 15% to 37%; psychiatrists, 6% to 25%; and neurologists, 5% to 15%. (Gadow, 1983; Rappley et al, 1995; Reid et al, 1994; Sandoval et al, 1976; Wolraich et al, 1990).

Comparative Treatment Rates for ADHD by Jurisdiction and by Minority Enrollment
In the Maryland ADHD medication survey of 1998, there was a five fold difference between the local school system with the lowest Ritalin treatment prevalence rate compared to that with the highest (1.18% vs.6.02%). A major portion of this variation appears to be explainable by regional differences in minority student enrollment. The jurisdictions with the lowest Ritalin prevalence rates in the survey were Prince George’s County and Baltimore City. These two had the highest minority enrollment rates in the state, 84.7% and 87.2%. The jurisdictions with the highest ADHD medication prevalence rates, Allegany and Garrett Counties, had among the lowest rates of minority student enrollment in the state, 4.0% and 0.7%. (Maryland, 1998)
Comparative Treatment Rates for ADHD by Jurisdiction and by Minority Enrollment - continued

In the fall of 1997, minority students represented 44.1% of the total public school enrollment in Maryland. Specifically, this included 36.1% African-American, 3.7% Hispanic, 4.0% Asian, and 0.3% Native American students. Nonetheless, the Maryland State Board of Education survey found that the state’s non-Caucasian students received only 23.7% of the Ritalin for ADHD which was administered in school. Specifically, this included 20.95% African-American, 1.79% Hispanic, 0.85% Asian, and 0.17% Native American students.

These disparities match those reported by Zito et al (1998b) who analyzed methylphenidate (Ritalin®) prescription claims in the Maryland Medicaid database by race/ethnicity in 1991 and found that African-American youth ages five-fourteen were prescribed methylphenidate at approximately 40% of the rate of their Caucasian counterparts. LeFever et al (1997) and Bussing et al (1998a) similarly found distinctly lower rates of stimulant treatment in minority student populations and for those in lower socioeconomic circumstances.

Special Education, ADHD and Stimulant Medication Treatment
Forness (1998) reviewed seven research studies and concluded that 29% of U.S. students receiving special education services for learning disabilities (LD), emotional disturbances (ED) and ‘other health impairments’ (OHI) categories met the diagnostic criteria for ADHD. The percentage with ADHD was highest for ED (43%), next for OHI (40%), and lowest for the LD (26%) category. Since the overall rate of ADHD amongst youth ages five to fourteen is in the range of 5% to 8%, those students identified as handicapped, and therefore assigned to receive special education services, have a far higher rate of ADHD.

The rate of Methylphenidate treatment for Maryland public school students receiving special education services is over six times higher than the rate for regular education students (8.7% vs. 1.36%). Since 12.6% of the entire student body in Maryland public schools receive special education services, and 8.7% of these students receive Ritalin in school, the fact that nearly half (45%) of the students who are receiving Ritalin are being served in special education becomes understandable. Reid et al (1994) report a similar proportion of public school students receiving stimulant medication who are enrolled in special education.

The rate of stimulant medication treatment is highest in self contained, elementary school special education classes (Safer and Krager, 1988) and far lower for primarily mainstreamed middle school students receiving special education services (Cullinan et al, 1987).
School Policies Concerning Methylphenidate Treatment for ADHD

Faussner (1998) from the U.S. Drug Enforcement Administration wrote that "a review of practices employed by schools for the handling of medication indicated that most schools did not have a nurse dispensing medication, few schools kept records of drugs given to students, and many schools allowed students to carry or administer their own medication."

The Maryland State Department of Education and the Department of Health and Mental Hygiene have written, "Guidelines for the Administration of Medication" (Maryland, 1997) in all the state's schools. Some schools in this state do not have a nurse administering medication due to financial limitations, although a registered nurse must supervise non-medical personnel in this process. In Maryland, written records are kept on all administered medications, and students are not allowed to carry medications for conditions such as ADHD on their person (Taliaferro, personal communication).

In a Wisconsin school district study, Musser et al (1998) reported that 37% of schools indicated that stimulant medications were kept in an unlocked cabinet, 83% of the schools had a school policy regarding the dispensing of medication (77% of which were written), 9.4% of the schools allowed students to carry their own ADHD medication, and the administration of medication for ADHD was most often done by members of the school office staff.

Efficacy and Effectiveness of Methylphenidate Treatment

In numerous clinical trials (systematic, short term research studies), methylphenidate treatment has resulted in a substantial lessening of the core ADHD features for approximately 75% of symptomatic children and youth (Du Paul et al, 1998). In the recent NIMH study of 579 students, (six site, fourteen month duration, multi-modal treatment) of children and youth with combined type ADHD, the monthly monitored stimulant therapy resulted in maintained and very significant benefits throughout the treatment period (Jensen and Payne, 1998). Similarly successful one to two year stimulant treatment results have been obtained by Gillberg et al (1997), Hechtman and Abikoff (1995), and Schachar et al (1997).

In two small studies of stimulant treatment in the community, the results have been less favorable in part because the medicated students were unselected, the treatment monitoring was less systematic, and medication non-adherence was probably greater. In the Rowland et al (1998) study in North Carolina, 38% of the elementary students receiving stimulant treatment were found not to be appreciably benefiting. In the Safer and Krager (1989) study, 14% of the elementary school students and 44% of the secondary school students receiving stimulants in Baltimore County, Maryland were still recorded at the end of the school year as showing the major features of ADHD. No other such studies in the medical literature have been located.
School-Physician Communication Concerning Students Diagnosed with ADHD

Wolraich (1997) wrote that "communication between the physician and teachers is a key factor in a successful plan for a child with ADHD." Most physicians who respond to surveys report that they do receive school and teacher reports concerning a child being diagnosed or in treatment for ADHD (American Academy of Pediatrics, 1998; Kwasman et al, 1995; Wolraich et al, 1990; Zarin et al, 1998). They do not, however, document the frequency and regularity of this communication. Far more revealing data on this issue come from surveys of parents and teachers and from an assessment of medical records. These reveal that in the majority of cases, there is no school-physician communication regarding the diagnosis and particularly the treatment of children and youth with ADHD (Barbaresi and Olsen, 1998; Bussing et al, 1998b; Goldberg et al, 1984; Jensen et al, 1989; Jerome et al, 1994). In practice, it is the parents, not the teachers, who supply the bulk of the data on the child's behavior and the treatment response (Wolraich, 1998). This is unfortunate because teachers are far more reliable reporters of the ADHD pattern than are parents (Achenbach et al, 1987).

The Abuse of Methylphenidate

The AMA Council on Scientific Affairs (Goldman et al, 1998) recently wrote the following: "There is little disagreement that stimulants as a class have marked abuse potential. However, stimulants differ in their ability to produce euphoria and thus liability to abuse. Almost all reports of abuse of methylphenidate itself have been of poly-substance abusing adults." In the annual survey of drug use by high school seniors conducted by the University of Michigan between 1991 and 1994, the "lifetime non-medical methylphenidate use has remained essentially constant around 1%". In 1995, the rate was reported to be 0.8% (Maurer, 1996).

The Drug Abuse Warning Network data on emergency department visits revealed a six fold increase between 1990 and 1995, but these were "overwhelmingly young women not ADHD male children and youth and adolescents..." Only two cases of methylphenidate abuse by adolescents with ADHD and only two cases of methylphenidate abuse by parents of children and youth taking it have been reported in medical literature (Goldman et al, 1998).

The Drug Enforcement Administration has had reports of thefts of methylphenidate, street sales, drug rings, illegal importation from outside the United States, and illegal sales by health professionals. There have also been thefts of school supplies of methylphenidate (Goldman et al, 1998).

There have been anecdotal reports of the misuse of methylphenidate at some college campuses. College students, without a legitimate diagnosis of ADHD, allegedly use the drug as a study aid reportedly because it increases their concentration.
Non-pharmacological Treatments of ADHD: Rationale and Approaches

Psychological approaches used in the treatment of ADHD necessarily include an educational dimension to make parents, teachers and youth aware of the aspects, treatments, ramifications, and usual course of ADHD. Education a vital first approach to treatment.

Goldman et al (1998) and members of the AMA Council on Scientific Affairs recently concluded that "non-pharmacological treatment modalities are well accepted and probably underused..." In a recent analysis of the scientific literature on this subject, entitled "Empirically supported psycho social treatments for attention deficit disorder," Pelham et al (1998) more specifically concluded that "behavioral parent training and behavioral interventions in the classroom meet criteria for well established treatments." The recommended treatments include: 1) systematic parent approaches to better structure the home life for the ADHD child; 2) school to parent to school behavior reinforcement systems; and 3) classroom-based behavioral programs such as token economies. These behavior management approaches require a major commitment by the adults involved and they take time, but they have been shown for three decades to be effective for the treatment of ADHD, particularly for mild and moderate cases (DuPaul and Eckert, 1997).

Psychological treatments are often used in conjunction with stimulant treatment to augment the effect of the medication. As such, they constitute a major component of what is known as multi-modal treatment. Although the recent large, NIMH study clearly supported careful and regular medical management as the single most measurably effective treatment for combined hyperactive and inattentive ADHD youth ages 7-9, Jensen and Payne (1998) stressed in their summary of multi-modal intervention that there is good evidence that psychological therapies in conjunction with stimulant treatment offer advantages over medical management alone.

Psychosocial therapies continue to play a major role in treatment for children and youth with problems that are commonly associated with--but not part of--the ADHD diagnostic profile. Such associated difficulties, known as comorbid behavior disorders, include learning disabilities, disruptive behavior disorders, anxiety, and depression. Some of these co-morbid symptoms, such as anxiety and low self esteem, may be an outgrowth of the maladjustment produced by ADHD.

Psychological approaches used to treat comorbid disorders are varied. They include psycho dynamic, supportive and behavioral approaches applied via individual, group and family therapy. Social skills training is one approach that is in its ascendency. When successful, these psycho social treatments achieve the following: lessen parent child rearing stress; promote parental harmony in home management; increase the child’s social skills; increase the resolution of conflicts; lessen excessive punishment practices; support the child’s areas of skill; improve medication adherence; and allow for a lower dose of medication treatment.
References


References - continued


Diagnostic and Methylphenidate Information
Diagnostic Criteria for Attention-Deficit/Hyperactivity Disorder

B. 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 school work or homework)
(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 six 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
(a) often blurts out answers before questions have been completed
(b) often has difficulty awaiting turn
(c) 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 7 years of age
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, disassociative disorder, personality disorder.)

Code base 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, Predominately Inattentive Type: if Criterion A1 is met but Criterion A2 is not met for the past 6 months
314.01 Attention-Deficit/Hyperactivity Disorder, Predominately Hyperactive-Impulsive Type: if Criterion A2 is met but Criterion A1 is not 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.

(DSM IV, 1994)
PRESCRIBING REGULATIONS FOR CONTROLLED DRUGS
(ITALIN AND AMPHETAMINES)

Both Federal and State laws classify Ritalin and amphetamines as Schedule II drugs. The State laws tend to mimic the Federal code. The Maryland law defines a Schedule II drug as one that:

- has a high potential for abuse, and
- is currently accepted medical use in the United States, or currently accepted medical use with severe restrictions, and
- may lead to abuse with severe psychic or physical dependence.

Opiates and other narcotic agents are included in this class of drugs. There is debate as to the appropriateness of methylphenidate’s inclusion as a Schedule II drug.

All prescriptions for controlled drugs need to be dated and signed on the day issued and must bear the full name and address of the patient, the drug name, strength, dosage form, quantity prescribed, directions for use, and the name, address and registration number of the practitioner.

The refilling of a prescription for a controlled and dangerous substance is prohibited.

A prescription for Ritalin may be called in to a pharmacy if it is followed up by a written prescription. The amount of the drug that the pharmacist may dispense is only enough for the emergency period.

A prescriber may write for any legitimate supply, however, the pharmacist cannot "divide" the prescription. In the case where a patient’s insurance restricts quantity, the pharmacist should inform the prescriber that the quantity dispensed was reduced by patient or insurance company request.
RITALIN

Ritalin, also known by its generic name methylphenidate, is the most widely used medication to treat Attention Deficit Hyperactivity Disorder in both youth and adults. Ritalin was commercially released in 1957. In the 1970's, its sales surpassed those of the amphetamines (Dexedrine and Benzedrine), which had been used since the 1930's for the treatment of various childhood behavior disorders.

Ritalin appears to act by increasing the availability of a brain neurotransmitter called dopamine. Its major effects are to increase a patient's ability to remain focused and to lessen restlessness. When it increases attention, children with ADHD can complete more classwork. When it reduces restlessness, it usually also lessens impulsive and disruptive behaviors. When effective, it leads to more positive relationships between the child and his teachers and parents.

Ritalin is manufactured in five, ten, and twenty milligram tablets. The medication when given in a therapeutic dose is usually effective within 30 minutes after administration. Its effects peak at one to two hours and it is usually effective for three to four hours. It is authorized by some parents only on school days. Other parents give the medication after school and on weekends because of its effects on impulsiveness and restlessness. The drug comes in a 20 milligram time release tablet which results in a lower blood level and stays in the system longer, but tends to be less effective.

The side effects of Ritalin are for the most part mild. Most common is an appetite reduction for the first two hours after taking the medication tablet. This effect can result in an initial lessening of a child's customary weight gain. Such an effect can be reversed by giving the child more food in the early evening when his appetite fully returns. The appetite decrease gradually lessens after about four months into the medication treatment. Insomnia may occur if the medication is administered in the late afternoon or in the evening. Mild stomach aches and headaches have been reported. These also decrease with regular use. Most physicians start the medication at a low dose and increase it gradually to achieve an effective result.

Tic movements, usually of the muscles around the eye orbit, but occasionally in the limbs and shoulders, are an infrequent side effect that can occur particularly in ADHD children with a family history of tic movements. These tend to lessen over time and with a dose decrease and are by no means an absolute contra-indication to stimulant treatment. Hallucinations are a rare side effect that ceases following a dose reduction.

Ritalin can be abused, primarily by adults who do not have ADHD. Treatment by youth with ADHD does not increase the likelihood of later drug abuse. Ritalin is in the stimulant category of drugs, like amphetamines and cocaine, but the drug does not substitute for cocaine in the treatment of cocaine addiction. In the treatment of ADHD, it has not resulted in lethality.
Summary of Public Testimony
Summary of Public Testimony

Organized by type of concern/comment; numbers indicate that more than one person expressed this concern.

Need for General Information
- Concern about dangers of medication, addictive potential, long-term side effects (3)
- Question about prevalence of ADHD in population, increasing numbers?
- Diagnosis of ADHD: Who makes it, how; when to re-evaluate (5)
- Parents need information (from doctors, from schools, in general) (2)
- Need more studies of ADHD

Specific Medication Concerns
- Medication can make a positive difference (4)
- Medication was helpful but it wasn’t enough; multiple interventions needed; behavioral methods (5)
- Medication was not effective
- Alternative treatment modalities were employed and effective: Feingold diet, other diet/nutritional plans; address "toxic" environmental causes of ADHD (5)

Concerns with Systems of Care I: Medical System
- Third-party payers don’t support proper evaluation and management of children with ADHD
- Doctors over-prescribe medication; prescribe without complete evaluation (5)
- Some doctors do not follow-up or monitor progress
- Doctors should take more responsibility for sharing information with schools
- Doctors never inform parents of alternative treatments available

Concerns with Systems of Care II: Education System
- Identification, Evaluation, and/or Diagnosis
  - It is too easy for the school to make the diagnosis and send the parent to the doctor for medication, which end up being all that is done for the child (5)
  - Teachers miss students who are inattentive but not hyperactive
  - Teachers are not allowed to say "Test"; parents must recognize the problem and request testing.
  - School system isn’t parent friendly—uses jargon (IEP, ARD) and resists parent involvement in the process
  - Schools do not inform parents of alternatives
  - Teachers should not say "he needs Ritalin."
  - Some teachers/administrators refuse to believe ADHD is a real disorder and has an adverse impact on student performance (3)
  - There are long delays in testing and getting help for students (5)
  - The school refuses to accept the outside testing
  - The school system did a good job testing
  - Schools can be good at picking up problems early and alerting parents to go to the pediatrician

- Treatment
  - There is a need for a treatment team in school (3)
  - Some teachers/administrators will not make accommodations even though there is a treatment plan (3)
Public Hearings Summary - continued

- **Treatment** - continued
  - Schools should teach social skills to these students (3)
  - The teachers were cooperative with behavioral interventions before we tried medication
  - Schools have established procedures for in-school medication management
  - Schools should treat each child as an individual and provide in-school supports beyond medication
  - Some schools are excellent at working with students with ADHD and their families
  - Most children receiving stimulant medication in our country receive it at school
  - Middle & high school teachers don’t keep parents informed when problems arise (2)

- **Service Coordination/Interdisciplinary Collaboration**
  - School nurses can case-manage and maintain communication with parent, teacher, and doctor (2)
  - The child should attend the ARD meeting; all members of the team need to attend in order to know their part in the plan
  - The school did not cooperate with the doctor
  - There is resistance to social workers in schools

- **Staff Development**
  - Teachers need accurate current information (4)
  - Teachers need training to make accommodations
  - School support staff do not know enough (2)

- **Other/General**
  - There is a discrimination against children with ADHD; stigma attached to taking Ritalin (2)
  - Many parents with children with ADHD may be home-schooling their children instead of dealing with the school system at all
  - Poor educational practice and large class size produce behaviors that look like ADHD

**Philosophical/Moral Concerns**

- Children are being violated, given drugs
- ADHD is not a real disease
- State institutions (school systems, MSDE, DHMH) resist/deny evidence that medication doesn’t work or is harmful
- Workplaces, colleges do not readily accommodate to needs of ADHD adults (2)

**Recommendations for Task Force**

- Need for State guidelines and uniform procedures re: Diagnosis/identification of children and youth with ADHD; treatment and monitoring progress and outcomes
- School should train teachers in accommodations (2)
- Teachers, administrators, and support staff should receive pre-service training in college
- Schools need increased funding to improve services for students with ADHD (2)
- MSDE should develop protocols for working with ADHD students
- Develop a balanced reading list and provide information for parents
- Consider need for legislation
- Make final Task Force report widely available to General Assembly, public and private schools, and the general public
ADHD Medication Prevalence Survey
ADHD Medication Prevalence Survey of Maryland's Public School Children

Purpose of the Study
The 1997 Maryland General Assembly passed House Bill 971 establishing the Task Force to Study the Uses of Methylphenidate and Other Drugs on School Children. The specific charge to the Task Force addressed by this study was to: "Determine the prevalence of the use of methylphenidate among school-age children in the State; determine the extent to which treatments for attention deficit/hyperactivity disorder other than methylphenidate are generally available or in use; and determine who prescribes methylphenidate to school-age children and why." This study represents part of the data collection done in order for the Task Force to meet its charge.

Method
Data Source
School health services staff (school nurses) in all Maryland public school systems were surveyed in April 1998 to determine the prevalence of methylphenidate (Ritalin) and other medications prescribed by physicians or other health care providers for treatment of attention deficit/hyperactivity disorder (ADHD) that were being dispensed during the school day. School health staff reviewed either student cumulative records or student health records in order to respond to the survey (Appendix A). No student was interviewed and data were reported in aggregate form at the local school system level in order to maintain confidentiality. Local school systems provided information for elementary, middle, and high school level students. Local school systems determined the grade structures of those designations.

In addition to survey data, student enrollments used in analyses were obtained from the MSDE September 30, 1997, enrollment data and December 1, 1997, Special Education Child Count data. Elementary totals were aggregated for grades pre-kindergarten, kindergarten, and grade 1 through grade 5. Middle totals were aggregated for grade 6 through grade 8 and high school totals were aggregated for grade 9 through grade 12. The resulting totals were: elementary = 410,664, middle = 183,803, high = 221,998, and total = 816,465.

Special education enrollments were similarly aggregated to the elementary level (50,955), the middle school level (27,602), the high school level (24,584), and total (103,141).

Type of Data
The survey instrument designed for this study collected information on students receiving Ritalin during school hours and also collected information on students receiving other medication during school hours for the treatment of ADHD. Students receiving medications only for conditions other than ADHD were not counted. Children with a diagnosis of ADHD but not receiving medication at school were not counted. The race/ethnicity and gender of each student receiving Ritalin and/or other medications for ADHD were reported. A student could be reported twice if he/she were receiving both Ritalin and another medication for ADHD.
Prevalence Survey

The data collection methodology and the survey instrument did not permit identification of students who were receiving Ritalin and other medications. Also, school health staff reported whether a student had a Special Education Individual Education Plan (IEP), a 504 Accommodation Plan, or no formal plan addressing a disabling condition.

The type of medical specialty of the prescribers of both Ritalin and other medications were reported. However, if a student was receiving both Ritalin and other medications for ADHD, then school health staff were instructed to report the specialty only in the section for Ritalin. Additionally, data were collected regarding the type of medications for treatment of ADHD other than Ritalin that were being dispensed during the school day.

Limitations

The major limitation in this study is that the data represent only children receiving medication for ADHD during school hours and not children receiving medication for ADHD at home or in other non-school settings. Thus, the estimates of children receiving medication for ADHD provided by this study are probably conservative. Additionally, there were minor differences between the total counts of students by gender, race, and special education identification for both children and youth receiving Ritalin and those receiving other medications. These missing data have been noted in the tables that present the results.

Results

The results are presented in tabular form for the State and for each local school system (LSS). There is a total of six tables. Both state and LSS data are in Appendix B. This section will describe the contents of each table using state data. Each local school system table was created in the same way and can be read similarly.

Table 1

<table>
<thead>
<tr>
<th>Percent of Enrollment Receiving Ritalin*</th>
<th>Percent of Enrollment Receiving Other Medications*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary (N = 12,774)</td>
<td>(N = 5,338)</td>
</tr>
<tr>
<td>3.11</td>
<td>2.90</td>
</tr>
</tbody>
</table>

* A single student may be counted as receiving both Ritalin and Other Medications.

Table 1 presents the percentage of enrollment receiving Ritalin and/or other medications at the elementary, middle, and high school levels. The Ns in parentheses are the actual numbers of students reported in the survey. For instance, 20,050 students statewide or 2.46% are receiving Ritalin in all Maryland public schools. Similarly, 3,721 students or 0.46% are receiving other medications. Some students may be counted in both categories since they may be taking more than one medication for ADHD. However, this survey indicates that no more than 2.46%+0.46% or 2.92% of all students in Maryland public schools are receiving medications in school for ADHD. The actual percentage is between 2.46% and 2.92% but these data do not permit a precise determination.
Table 2

<table>
<thead>
<tr>
<th></th>
<th>Percent of Students Receiving Ritalin* By Type of School</th>
<th>Percent of Students Receiving Other Medication* By Type of Schools</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Elementary (N = 12,774)</td>
<td>Middle (N = 5,338)</td>
</tr>
<tr>
<td>American Indian</td>
<td>0.18</td>
<td>0.17</td>
</tr>
<tr>
<td>Asian</td>
<td>0.82</td>
<td>0.96</td>
</tr>
<tr>
<td>White</td>
<td>73.11</td>
<td>78.83</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.68</td>
<td>2.06</td>
</tr>
<tr>
<td>Male</td>
<td>77.87</td>
<td>81.02</td>
</tr>
<tr>
<td>Total</td>
<td>63.71</td>
<td>26.82</td>
</tr>
</tbody>
</table>

*A student may be counted as receiving both Ritalin and Other Medications.

Table 2 presents the percentage of the reported students receiving Ritalin and/or other medications at the elementary, middle, and high school levels by race/ethnicity and gender. The majority of students (73.11%) receiving Ritalin were white and 69.73% of students receiving other medications were white. Males receiving Ritalin as well as other medications outnumber females by approximately three to one (77.87% to 21.19%, respectively.) A majority of students receiving Ritalin or other medications, irrespective of race or gender, were in the elementary grades (63.71% and 60.36%, respectively).

Table 3

<table>
<thead>
<tr>
<th></th>
<th>Percent of Students With and Without IEPs/504 Plans Receiving Ritalin*</th>
<th>Percent of Students With and Without IEPs/504 Plans Receiving Other Medications*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Elementary (N = 12,592)</td>
<td>Middle (N = 5,298)</td>
</tr>
<tr>
<td>With IEP</td>
<td>43.33</td>
<td>48.17</td>
</tr>
<tr>
<td>With 504 Plan</td>
<td>7.24</td>
<td>9.55</td>
</tr>
<tr>
<td>Without IEP or 504</td>
<td>48.43</td>
<td>44.28</td>
</tr>
<tr>
<td>Total</td>
<td>62.96</td>
<td>26.49</td>
</tr>
</tbody>
</table>

*A single student may be counted as receiving both Ritalin and Other Medications

Table 3 presents the percentage of enrollment receiving Ritalin and/or other medications at the elementary, middle, and high school levels that had IEPs, 504 Plans, or neither IEPs nor 504 plans. The Ns in parentheses are the actual numbers of students reported in the survey. There were nearly equal percentages of students receiving Ritalin that had IEPs (43.33%) compared with students who had neither an IEP or 504 plan (46.84%). The differences in total row statistics between Table 2 and Table 3 are due to missing data.
Prevalence Survey

Table 4

<table>
<thead>
<tr>
<th></th>
<th>Percent of Special Education Enrollment</th>
<th>Percent of Special Education Enrollment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>With IEPs Receiving Ritalin*</td>
<td>With IEPs Receiving Other Medications*</td>
</tr>
<tr>
<td>Elementary</td>
<td>(N = 5,456)</td>
<td>(N = 1,147)</td>
</tr>
<tr>
<td>Middle</td>
<td>(N = 2,446)</td>
<td>(N = 566)</td>
</tr>
<tr>
<td>High</td>
<td>(N = 1,069)</td>
<td>(N = 198)</td>
</tr>
<tr>
<td>Total</td>
<td>(N = 8,971)</td>
<td>(N = 1,911)</td>
</tr>
<tr>
<td></td>
<td>10.71</td>
<td>2.25</td>
</tr>
<tr>
<td></td>
<td>8.86</td>
<td>2.05</td>
</tr>
<tr>
<td></td>
<td>4.35</td>
<td>0.81</td>
</tr>
<tr>
<td></td>
<td>8.7</td>
<td>1.85</td>
</tr>
</tbody>
</table>

* A single student may be counted as receiving both Ritalin and Other Medications.

Table 4 presents the percentage of Special Education enrollment receiving Ritalin and/or other medications at the elementary, middle, and high school levels that had IEPs. The Ns in parentheses are the actual numbers of students reported in the survey. For instance, 10.71% of Special Education students at the elementary level are receiving Ritalin while 2.25% are receiving other medications. The counts may be duplicated and, thus the actual total count is between 10.71% and 10.96%. At the elementary level, special education students are nearly five times more likely to receive Ritalin rather than other medications (10.71% vs. 2.25%).

Table 5

<table>
<thead>
<tr>
<th></th>
<th>(REVISED) Percent of Prescriptions by Provider* for Ritalin</th>
<th>(REVISED) Percent of Prescriptions by Provider* for Other Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Elementary (N = 12,516) Middle (N = 5,245) High (N = 1,878) Total (N = 19,639)</td>
<td>Elementary (N = 2,180) Middle (N = 1,021) High (N = 418) Total (N = 3,619)</td>
</tr>
<tr>
<td>Pediatrician</td>
<td>62.75 56.35 42.82 59.13</td>
<td>43.42 38.39 34.82 41</td>
</tr>
<tr>
<td>Family Practitioner</td>
<td>13.19 18.33 27.15 15.9</td>
<td>9.06 15.16 14.82 11.45</td>
</tr>
<tr>
<td>Behavioral Clinic</td>
<td>4.84 3.2 2.92 4.22</td>
<td>7.93 6.72 6.12 7.38</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>2.75 11.25 16.71 10.52</td>
<td>28.67 25.72 35.76 28.66</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>5.7 1.75 1.46 2.36</td>
<td>1.98 2.59 2.59 2.23</td>
</tr>
<tr>
<td>Not Known</td>
<td>2.79 7.81 7 6.39</td>
<td>7.21 9.4 4.26 7.49</td>
</tr>
<tr>
<td>Other</td>
<td>1.49 1.32 1.93 1.48</td>
<td>1.71 2.02 1.65 1.79</td>
</tr>
<tr>
<td>TOTAL</td>
<td>63.73 26.66 9.61</td>
<td>60.19 28.28 11.53</td>
</tr>
</tbody>
</table>

* Providers of Ritalin and Other Medications to the same student were recorded in the Ritalin category.

Table 5 presents the percentage of prescriptions for Ritalin and/or other medications at the elementary, middle, and high school levels by type of medical specialty. The Ns in parentheses are the actual numbers of prescriptions reported in the survey. Since prescribers may have prescribed both Ritalin and other medications and were intentionally counted only with Ritalin medications, the actual number of other prescriptions may be greater than reported. Additionally, the total number of prescribers may be less than the number of children since one prescriber may treat more than one child. Pediatricians wrote the largest percentage of prescriptions in both the Ritalin and other medications categories (59.13% and 41.00%, respectively).
Prevalence Survey

Table 6

<table>
<thead>
<tr>
<th>Medication</th>
<th>Elementary (N = 2,322)</th>
<th>Middle (N = 1,157)</th>
<th>High (N = 452)</th>
<th>Total (N = 3,931)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adderall</td>
<td>30.45</td>
<td>32.41</td>
<td>28.10</td>
<td>30.76</td>
</tr>
<tr>
<td>Catapres</td>
<td>11.33</td>
<td>12.10</td>
<td>5.75</td>
<td>10.91</td>
</tr>
<tr>
<td>Cylert</td>
<td>2.15</td>
<td>3.20</td>
<td>4.20</td>
<td>2.70</td>
</tr>
<tr>
<td>Dexedrine</td>
<td>43.80</td>
<td>36.99</td>
<td>50.66</td>
<td>42.58</td>
</tr>
<tr>
<td>Norpramin</td>
<td>0.34</td>
<td>0.95</td>
<td>0.00</td>
<td>0.48</td>
</tr>
<tr>
<td>Pamelor</td>
<td>0.65</td>
<td>0.95</td>
<td>0.00</td>
<td>0.66</td>
</tr>
<tr>
<td>Torfranil</td>
<td>1.03</td>
<td>1.38</td>
<td>0.66</td>
<td>1.09</td>
</tr>
<tr>
<td>Wellbutrin</td>
<td>0.99</td>
<td>2.25</td>
<td>3.32</td>
<td>1.63</td>
</tr>
<tr>
<td>Other</td>
<td>9.26</td>
<td>9.77</td>
<td>7.30</td>
<td>9.18</td>
</tr>
<tr>
<td>TOTAL</td>
<td>59.07</td>
<td>29.43</td>
<td>11.50</td>
<td></td>
</tr>
</tbody>
</table>

Table 6 presents the percentages of other medications at the elementary, middle and high school levels as well as totals. As shown in prior tables, most prescriptions (59.07%) were at the elementary level while the most frequently prescribed medication other than Ritalin was Dexedrine (42.58% overall) followed by Adderall (30.76%).

Summary

Approximately 2.5% of children in Maryland public schools receive Ritalin and/or other medications for ADHD during school hours from school health services staff. Roughly 8 out of 10 students receiving medications for ADHD at school are males. Pediatricians are most likely to be the prescribers of all medications for treating ADHD. Psychiatrists prescribed other medications most often (29.2%) after pediatricians (41.8%). Substantial percentages of students receiving both Ritalin and other medications (46.8% and 39.9%, respectively) had neither an IEP nor 504 plan. Relatively small percentages (8.7% and 1.85%, respectively) of special education students were reported to be receiving either Ritalin or other medications for ADHD.
Public School Students on Medication for ADHD
by Jurisdiction

Prevalence of the Use of Methylphenidate in Counties of Maryland
The Maryland Interdisciplinary Conference on ADHD
Maryland’s HB 971 charged the Task Force to Study the Use of Methylphenidate in School Children to "convene a statewide conference on Attention Hyperactivity Disorder that would be appropriate for parents, teachers and primary care physicians to examine the latest information on Attention Hyperactivity Disorder, the use of methylphenidate, dextroamphetamine, magnesium pemoline, and other medications effective in the treatment of the disorder, and non-pharmacological interventions in the treatment of Attention Deficit Hyperactivity Disorder."

On November 13 and 14, 1998, a statewide conference - The Maryland Interdisciplinary Conference on Attention Hyperactivity Disorder - was held in College Park, MD. The conference was sponsored by the Task Force to Study the Use of Methylphenidate in School Children, the Maryland State School Health Council, the Maryland State Department of Education, the Department of Health & Mental Hygiene, the Governor’s Office on Children, Youth and Families, and the University of Maryland School of Medicine.

The two day conference brought parents, educators, counselors, psychologists, pharmacists, school nurses and primary care physicians together to examine the latest information on Attention Deficit Hyperactivity Disorder (ADHD) and its treatment. Dr. Sidney Seidman, chair of the Task Force to Study the Use of Methylphenidate in School Children moderated the conference and presented results of the Task Force’s findings. Keynote speakers included:

Dr. Larry B. Silver  
Child & Adolescent Psychiatrist, Author and Assistant Professor of Psychiatry  
Georgetown University Medical Center

Dr. Peter Jensen  
Chief, Developmental Psychopathology Research Branch, National Institute of Mental Health

Dr. Patricia O. Quinn, Developmental Pediatrician, and author

Kathryn Coleman, Director of Pupil Services and Special Education  
Calvert County Public Schools

Dr. Martin Wasserman, M.D., J.D., Secretary  
Maryland Department of Health and Mental Hygiene

Richard Steinke, Deputy State Superintendent  
School Improvement Services Office  
Maryland State Department of Education

Dr. Barbara Ingersoll  
Clinical Psychologist, Clinical Associate Professor, West Virginia University
MD Interdisciplinary Conference on ADHD

Thirty workshops were offered on a variety of topics that addressed issues surrounding the treatment of attention deficit hyperactivity disorder including the use of methylphenidate and other medications, non-pharmacological interventions and supports for families and educators. Workshops offered information for both professionals treating and interfacing with ADHD children, and for parents of children with ADHD.

The total attendance for the conference for both days totaled 544. Fifty-eight (58) speakers from a variety of fields, including task force members with expertise and knowledge in the field and ADHD, presented the thirty workshops. Of the registered participants approximately 150 parents attended. Approximately 280 professionals attended as well, including:

140 local school system representatives
30 local health department representatives
37 private health care practitioners
34 private mental health providers
26 private school representatives
20 University professionals
12 Department of Health and mental Hygiene staff
21 Maryland State Department of Education staff
58 Speakers and task force members

Tapes of each of the conference sessions were made and are available to the public through contacting Donna Behrens, Conference Chair, Maryland State School Health Council at 410-767-4269. A complete copy of the conference agenda is located in the supplemental appendix of this document.
SUMMARY OF REPORT OF FINDINGS OF FOCUS GROUP MEETINGS
LESSONS FROM LISTENING TO PARENTS OF ADHD CHILDREN

Task Force To Study the Uses of Methylphenidate
and Other Drugs on School Children

Bruno J. Anthony, Ph.D. and Laura G. Foster, Ph.D.

Maryland Centers for Attention and Developmental Disorders
Department of Psychiatry, University of Maryland-Baltimore
BACKGROUND

The Task Force requested that the Maryland Centers for Attention and Developmental Disorders carry out a series of focus group discussions with parents around the State of Maryland to sample caretaker views on topics related to the referral, diagnosis, and intervention for children and youth with ADHD as well as the economic and social burdens placed on families. Groups were held in four distinct geographical areas of the state (East-Talbot County, West-Allegheny County, North-Baltimore City, South-Prince Georges County). Advertisements in local media outlets elicited responses from 88 parents of school age children and youth with ADHD of whom 58 were selected for participation in the groups. In all, 42 parents attended with group size ranging between from five to twenty. The children and youth of the parents who attended ranged in age from four to seventeen and were representative of the characteristics of the ADHD population in general in terms of male to female ratio, age at diagnosis, and from whom they received services.

Drs. Anthony and Foster (Director and Associate Director of the MCADD) moderated the four two-hour discussions with the goal of encouraging all members to share their views, avoiding biased and judgmental questions and comments, and flexibly covering important topics derived from an outline of open-ended questions dealing with the diagnostic process, treatment, with particular emphasis on medication, the effects of having an ADHD child on family life, and interventions that have been most helpful. Discussions were audio-taped and full transcriptions prepared from which a list of content categories were derived along with the most useful and representative quotes related to the various ideas. Finally, categories containing the various ideas and quotations were clustered into themes. These themes provide the major headings for the following results section. Care was taken to incorporate comments and concerns of views that did not fit general themes or directions but still represented important input.

RESULTS

The focus group method of gathering information forced us to remove the filters of researcher, clinician, and “expert” which are usually adopted to screen material received from parents to fit with the purpose of the interaction. We simply listened and in that way, we were able to understand more fully the experience of families with ADHD children and youth. Parents emphasized again and again the stress involved in parenting an ADHD child. However, we were struck by the eloquence and humor they used in describing their experience. They needed little prompting to speak; the words poured out, varying in the elegance of their delivery but packing force, passion, and persuasiveness. Also, like soldiers in battle, it seemed to help many to maintain humor, often with a “black” quality to it.

By listening, we heard several important messages, quite consistently across groups, that reoriented our thinking about this complex disorder. First, parents viewed medication in generally positive terms but clearly communicated ambivalent feelings about its use. Second, in statement after statement, parents conveyed to us the weight of the burden that their ADHD children and youth confer, not only on them, but on others who care for and teach them. Third, shouldering this burden demands vigilance and a position of advocacy; to function best for their children and youth, parents feel the need to carefully monitor all aspects of their child’s life and to be informed, pushy, and persevering in the face of numerous obstacles and frustrations.
Summary of Report on Focus Group Meeting

Finally, the burden is reduced for parents when they sense that others appreciate their level of suffering and when they join with others who work with their children and youth in a spirit of cooperation.

I. Opinions concerning medication: "I think the medicine is really a start. I mean there’s a lot of work, a long way to go with... The medicine is a good start. It gives him the ability or the realization that he can do the work."

Parents almost universally viewed medication as an important tool in the treatment of ADHD, although many wished that they did not have to use it. Most hoped that their children and youth would be able to discontinue its use by developing skills to compensate for their difficulties. Some parents expressed ambivalent feelings concerning the use of medication, resulting from fears of untoward effects, stigma, worries that children and youth would use it as a crutch, and a desire to use more “natural” treatments. There was no sense from these parents that stimulants or other drugs were over prescribed. Instead, concerns were expressed over specific drawbacks of medication (e.g., uneven course of effects), seemingly random changes in dosage and medication type, negative side effects, and lack of communication with the prescribing physician. A resounding message was also that medication was not the total answer to the ADHD child’s problems. Rather, it was seen as an important tool but only when used in conjunction with other interventions to lower the burden of the disorder on the child, family, schools, and providers.

II. Burdens of ADHD: “He’s the joy of my life, but there’s a love-hate relationship going on almost daily. You know you love them but you could just slam dunk them sometimes”

The sense of burden permeated the comments of the four groups of parents. This is in keeping with other findings that externalizing disorders, like ADHD, produce the greatest burden based on their prevalence, severity, stability, and impact on the individual, family, and community. From the comments of parents, the burden of ADHD results from a variety of sources including community stigma, stresses of being on guard because of the impulsiveness of the child, the need to monitor social and academic activities, lack of community and family support, family conflict, and enforced isolation. Judging from our experience, the level of burden and the response of parents and caretakers to the burden may have major significance for outcomes of ADHD children and youth. Although little research exists in this area, recent studies have shown that increased levels of family-environment adversity, particularly family conflict, was associated with impaired psycho social functioning in ADHD children and youth.

Although parents were the sole voice in these focus groups, their comments also reflected the wider burden of ADHD. Teachers are confronted with a variety of challenges including engaging children and youth with less ability to be engaged and directing children and youth with greater tendency to resist direction. These challenges are complicated by a higher prevalence of learning disabilities and other behavioral and emotional problems. They also demand a greater degree of out-of-class time and activities, greater contact with parents, and alterations in their usual way of teaching.
Summary of Report on Focus Group Meeting

Parents are frustrated with the lack of response of teachers, but also realize the weight of the teachers' burdens and the lack of training and support available to meet these demands.

Judging from the parents' experiences with prescribing physicians, treating the ADHD child involves significant demands which their practice style has difficulty accommodating. Parents want their physician to hear their concerns and confusion about the diagnostic process, to conduct comprehensive evaluations, to provide advice on behavior management, school issues, family conflict, as well as to carefully monitor medication. Comments by parents also implied the sense of burden that their ADHD child carries above and beyond dealing with the core symptoms and associated problems. They often are shut out of activities such as boy scouts and sports teams. Their lives are restricted by the increased need for structure and their parents' vigilant attitude. They carry labels like "bad kid" and often engender negative comments from adults and peers.

III. Need for advocacy: "You need to stay on top of these teachers, these professionals, you need to be educated, you need to know what’s going on and you need to know your rights."

A significant aspect of the burden that parents carry is the need to be an advocate for their child. It was clear to nearly all the participants that they needed to develop a "siege" mentality to get needed help for their child. Our sense was that there was a developmental progression towards advocacy that was similar to stages identified in families dealing with members with severe mental illness. There is first a stage that could be called "What's wrong?" This occurs prior to diagnosis and involves rationalizing ("he's only a boy"), anger and stress over the symptoms, and finally a search for information and support. Once a diagnosis is achieved, a stage of Recognition occurs when the behaviors can be finally labeled. A range of emotions can occur at this time, including relief at finding an "answer" and guilt over prior responses to the child's problems. A critical stage then ensues that can be labeled Coping involves adjusting to frequent crises and disruptions as well as the development of despair and pessimism as the chronic nature of the disorder becomes evident. The family's response at this stage appears critical in adapting to the burden of ADHD. Parents who are most successful seem to move into a stage of Advocacy which involves increased assertiveness, decreased self-blame, and efforts to change the system at all levels. As we note in the 'Recommendation' section below, helping parents move toward such an advocacy position may have important effects on outcomes for ADHD children and youth. Although these stages appear to represent a developmental progression, it was our feeling that parents often shift back and forth between different stages depending on external events and as their ADHD children and youth met new challenges at different developmental and academic stages.

38
Summary of Report on Focus Group Meeting

IV. Needs for Acknowledgment and Cooperation: “What happens is, every once in a while, there’s a gem, a teacher is there and knows how to do it and you just say, “wow, we’re going to have a good year; and then the next year, if you get somebody who doesn’t want to do those things or doesn’t know how intuitively to do it, you just pay the price, and the kid pays the price. Our son paid a heck of a price. In our experience you just hope that you’ll make it through that year without too much damage.”

Strength, self-confidence and a sense of mastery derive from an advocate’s stance. However, it was clear from our parents that their crusade for their child is helped markedly by an acknowledgment of their burden by others coupled with a desire to collaborate and cooperate. The message was simple and direct. The genuine feelings conveyed by teachers, therapists, providers, and other in the community were just as important as the content of the interventions.

The need for interventions aimed at different aspects of ADHD children’s lives (e.g., school performance, family life, community activities) and the coordination of these interventions was a strong message that emerged from the focus groups. Parents’ understanding of the comprehensive type of treatment strategies needed to make effective progress with ADHD children and youth and it is in keeping with an emerging literature indicating that single treatments alone are unlikely to yield long-term, clinically-significant gains.

DIRECTIONS

Listening to parents participating in the focus groups allowed us to recognize that we need a shift of emphasis in the way that we approach the diagnosis and treatment of ADHD in school-aged children and youth. There is by far more research conducted on ADHD than any other disorder affecting children and adolescents, concentrating on topics such as diagnostic reliability and validity, neuropsychological and neurobiological etiologies, medication effects, and specific therapeutic interventions. However, according to our parents, these topics do not have as much relevance to the day-to-day functioning of ADHD children and youth as the stresses and burdens that accrue to their families, teachers, and providers. What we heard from parents and evidence from recent surveys (e.g., Hoagwood, 1998) reveals a disturbing trend in the treatment of ADHD that suggests less rather than more effective interventions. Although the amount of medication dispensed has increased over the last eight years, the provision of psycho social interventions and support services has generally declined.
Oddly, this change has occurred amidst calls for a broader model of intervention for childhood disorders (Hoagwood, Jensen, Petti, and Burns, 1996), moving away from a major emphasis on symptom reduction to including general adaptation, consumer perspectives (e.g., quality of life, satisfaction with care, family strain), environments (aspects of home, classroom, neighborhood, availability of social support), and systems (use of services, accessability, coordination, and costs). The focus group findings point to the need to develop interventions that directly address these broader outcomes. We need to expand our focus to a more systemic level, particularly within the Health and Education realms, to have impact on this major public health problem. Care has tended to be in pieces, concentrating on symptom management. We have neglected the pain and management needs of families. We feel that there is a strong need for support and cooperation to reduce the burden on all involved in the ADHD child’s life. Maryland has the opportunity to be a leader in this effort. Recommendations to begin to reduce stigma and the burden of ADHD on parents, teachers, and professionals as well as to develop coordinated, compassionate interventions to benefit ADHD children and youth in this State.

RECOMMENDATIONS

A. System Level Recommendations

Evidence from a variety of sources suggests that ADHD and its associated problems represent a major public health problem. It is one of the most common disorders of childhood and adolescence, and it creates significant burdens on individuals, families, and systems of care. Yet, there are few examples of system-wide initiatives to address this problem. We need to take a cue from one of our parents and begin to design more comprehensive responses to this problem.

“Well, it seems to me that what we have here is an epidemic and very widespread, and it needs to gain local and national attention with schools, administrators, teachers, parents, and so everyone’s on the same even keel, and education may be the key here.”

1. Develop consistent guidelines for assessment and intervention of ADHD within the public school system.

Parents were frustrated and confused by the response of school systems to the difficulties that their ADHD children and youth present academically and behaviorally. Factors which lead to this frustration included: (1) the wide variations in knowledge base concerning ADHD among school staff; (2) lack of adequate assessment and referral procedures; (3) confusion as to how to address the difficulties that ADHD children and youth possess within current IDEA (Individuals with Disabilities Act) guidelines; (4) lack of effective classroom interventions and/or difficulties in implementing such interventions by teachers; (5) lack of consistent monitoring of the implementation plans developed for ADHD children and youth; and (6) lack of involvement of parents in the decision-making and intervention process. Recently, the State Department of Education revised their Learning Disabilities Handbook.
Summary of Report on Focus Group Meeting

Although ADHD issues were considered, they dealt mainly with the overlap with specific learning disabilities. Given the high prevalence of ADHD and the burden it places on teachers, administrators, and parents, a Task Force to develop specific guidelines and best practices for assessment and treatment needs to be established along with a dissemination plan. Based on the process used to revise the Learning Disabilities Handbook, the Task Force should develop procedures in the following areas:

- Appropriate and operational assessment, evaluation, and diagnostic procedures
- Effective team processes
- Effective Individualized Education Programs (IEP)
- Monitoring the implementation of the IEP goals
- Specific classroom intervention and adaptation strategies
- Classroom management procedures
- Alternative or altered methods for evaluating student performance
- Family involvement and coordination between home interventions and school interventions
- Increased sensitivity to the parent’s and child's struggles with ADHD (reduction of stigma)
- Interventions at individual, family, classroom, school levels and incorporate behavioral, academic, and socio-emotional functioning
- Teacher and staff education about ADHD on an ongoing basis
- Formal teacher training in ADHD as part of their core educational curriculum
- The impact of ADHD on the learning environment
- Establishing and maintaining effective collegial and collaborative relationships with outside professionals involved in the care of the ADHD child

2. Mount a public awareness campaign

The sense of stigma that parents expressed resulted, in part, from misperceptions and misinformation from the media and from word of mouth. Negative perceptions would be helped by a coordinated, accurate campaign to provide balanced information about ADHD and its treatment. In addition, parent reports and other surveys indicate that lack of information represents a major barrier to care. This campaign should also work to increase the availability of community activities for ADHD children and youth and their families.

3. Prioritize the development and dissemination of "best practices" information for ADHD and encourage innovative interventions.

There are great costs and burdens felt by families, teachers and others involved in the care of children and youth with ADHD, yet parents felt somewhat pessimistic about the range of treatment options available to them. Therefore, new initiatives are needed, developed through collaboration of the Department of Education, The Department of Health and Mental Hygiene, and the resource center (see below), to increase awareness of ADHD and to provide innovative, effective treatments.
Summary of Report on Focus Group Meeting

- Parents reported wide variation among providers in the knowledge base concerning ADHD, diagnostic sophistication, and treatment options. There is a need to increase the knowledge base of providers in regards to diagnostic and treatment options in light of new studies and "best practices" guidelines.
- Develop methods to ease families' path to diagnosis and treatment.
- Set practical, relevant, research priorities.
- Launch the public awareness campaign designed to reduce the stigma of ADHD and increase access to appropriate services.
- Develop respite programs for families.
- Develop innovative community resources such as camps for children and youth with ADHD after school, homework and tutoring programs, etc.
- Develop an advocacy and case management system that can aid families in obtaining appropriate services until they are able to advocate for themselves. These advocates need not be professionals, but could be other knowledgeable parents who understand and have successfully navigated the "system" themselves.

4. Identify and support a resource center

These recommendations would benefit from input and coordination from a resource center on ADHD. The center(s) would perform a number of functions to aid in improving the quality of life for ADHD children and youth.

- In collaboration with consumer groups like CHADD, it would take the lead in designing and implementing the public awareness campaign to reduce misperceptions of ADHD, encourage the development of new community resources, and provide a central source of diagnostic and treatment information.
- Provide resources to collaborate with schools and school mental health programs in designing and implementing school-based interventions, like the support groups outlined above. The center should develop close ties to the active school mental health programs.
- Help develop material covering "best practices."
- Provide a sophisticated, multi-disciplinary program to evaluate children and youth who present with particularly difficult or hard to manage ADHD symptoms and/or associated problems.
- Provide the research expertise to evaluate the efficacy of new programs and interventions targeting ADHD children and youth.
Summary of Report on Focus Group Meeting

B. Provider-Level Recommendations

1. Intervene to reduce burden of ADHD on families
   The feelings conveyed by the parents in the focus groups suggest practices which would help reduce family burden and improve cooperation, and thus the care of ADHD children and youth. We feel that reducing the family's burden will result in improved outcomes for both the ADHD child and their families.

   • Recognize and acknowledge the stress and burden that an ADHD child brings to a family.
   • Reduce tendency to blame the parents for their child's behavior.
   • Challenge the view that ADHD children and youth are "bad" or "behavior problems.
   • Decrease the sense of isolation by increasing access to family members and community resources.
   • Develop ongoing support groups.
   • Help spread parenting responsibilities within families and in the outside community.
   • Assess the need for parents to be vigilant and modify accordingly.
   • Expand family therapy from an emphasis on parent training to a systems approach, concentrating on reducing burden by enhancing system coordination.

2. Intervene to reduce burden of ADHD on child
   When working directly with the child, goals of reducing the strains associated with the disorder should be considered part of the treatment plan along with symptom reduction.

   • Concentrate on school issues where the greatest burden and source of distress is felt.
   • Deal with child's sense of being different.
   • Develop group/community activities, perhaps through county recreation centers, which are accepting of ADHD children and youth. Such efforts could be modeled through successful summer and follow-up programs already in operation around the country.
   • Develop support groups for ADHD children and youth, ideally linked to schools, which address issues of school and family pressures and social rejection.

3. Help parents move toward an advocacy position
   It seemed from our focus groups that the families that were most successful in adapting to the burdens placed on them by having a child with ADHD were the parents who adopted an advocacy approach. The parents in our groups felt that this position had been forced on them by a lack of alternatives, and they repeatedly wished for help in adopting this position. Nonetheless, the parents who were strong advocates for their children and youth seemed to have a better outcome in terms of their own stress levels, and obtaining their child's needed services. Therefore, individual practitioners should aid parents in developing an advocacy position.
Summary of Report on Focus Group Meeting

- Empower parents by allowing them to be the primary decision-maker for their child’s services (rather than a professional).
- Provide psycho-educational services which would help parents become experts in ADHD.
- Allow parents to ask questions, bring in information that they have found on their own, and adopt an open and collaborative stance to their ideas.
- Recommend that parents become involved in support and advocacy programs in their community (e.g., CHADD, Learning Disabilities Association).
- Help parents find outside advocates as needed.

C. School-level Recommendations

1. **Intervene to reduce teacher burden and increase school-home cooperation**

   Parents acknowledged the burden that an ADHD child brings to the classroom teacher and school environment. The recommendations outlined below address increasing teacher expertise and skill level to provide solid tools to work with ADHD children and youth in the classroom.

   - Increase awareness of important aspects of ADHD (e.g., biological basis, problems are treatable but not curable, problems rest in performance not knowledge, the most effective interventions for the ADHD child’s school problems are school-based).
   - Increase communication between parents and teachers through developing trust, reducing emphasis on “family problems” as causal, increasing mutual awareness of the difficult challenges of dealing with an ADHD child.
   - Develop a cadre of "master teachers" to provide advice and support.
   - Provide ongoing collaborative consultation for teachers to work on engagement children and youth in the classroom, identifying problems, and developing and monitoring individualized programs.

2. **Develop integrated, school-based child, family, and teacher support groups**

   Parents felt that listening to other parents and gaining information and insight was a particularly important and useful enterprise. At the same time, they felt that their children and youth also carried a sizable burden and would benefit from peer support. Parents also believed that teachers often were operating without sufficient knowledge of ADHD and without ongoing support. Joint child, parent, and teacher support groups, occurring within the school context, appear an ideal forum to facilitate support and coordination among the different participants. The goal would be to address similar issues concerning ADHD, stressing understanding of the core and associated problems, the burdens carried by each partner, the development of appropriate interventions, and support in implementing the programs. The structure of these groups would incorporate well-developed components of existing family programs such as the following:

   - Defining ADHD and the different types of outcomes
   - Encouraging positive behavior and improving adult-child relationships
   - Balancing relationships at home and in the classroom
Summary of Report on Focus Group Meeting

- Avoiding conflicts
- Improving self-regulation
- Dealing with serious problems
- Developing problem solving techniques
- Developing appreciation of burdens carried by child, parent, and teacher

Each group would also have specific, tailored objectives. For ADHD children and youth, components would include dealing with the sense of being different, the uniqueness of ADHD, social skills training, managing transitions, and taking responsibility. Parent groups will emphasize developing the role of an advocate, parent-child relationship problems, communication, and home-based contingencies. Teacher groups will involve more specific assessment and intervention information, ways to improve communication with parents and students, stress management, and how to access consultative services.

D. Research Efforts

Reports from our parents are consistent with other research showing that most children and youth with ADHD receive some type of services at some point. However, it is not clear whether these services are appropriate, consistent, or meet standards of quality. In this vein, research should be supported and aimed at treatment studies carried out in service delivery settings where broad notions of effectiveness can be evaluated. Specific recommendations include:

- Expand the range of outcome measures to include assessments of burden and adversity.
- Evaluate interventions specifically targeting reduction in the burden (such as those outlined above) of ADHD on children and youth, parents, and teachers.
- Investigate more formally barriers to care, and methods to remove such barriers. Studies on how to best engage families in treatment, improve cooperation, and avoid mistrust are greatly needed.
- Research is needed to study the adequacy of the match between services for ADHD children and youth, both pharmacological and psycho-social, and treatment needs in community settings.
- Evaluation of school and community-based interventions
- Our parents acknowledged the burdens that ADHD puts on professionals, particularly pediatricians and family practice physicians who manage the majority of ADHD children and youth. More formal studies of these burdens and the barriers to adequate care that they impose need to be initiated.
Survey of Maryland Local School Systems on ADHD
SURVEY OF MARYLAND LOCAL SCHOOL SYSTEMS ON ADHD

I. Purpose, Methodology and Limits of the Survey

1. Purpose

- to determine current knowledge, policies (written and not written), and practices regarding children and youth with ADHD in the schools
- to offer an opportunity to express concerns and suggestions regarding working with children and youth with ADHD in schools and current school practices
- to help the task force identify issues that need to be addressed regarding children and youth with ADHD in schools, in families, and in the community
- to elucidate barriers to good practice and to suggest what might be done to overcome them
- to identify areas for further study and exploration

2. Method

A questionnaire was sent out to all 24 school systems in the State of Maryland in March, 1998. The cover letter was from Dr. Nancy Grasmick, State Superintendent, stating the purpose of the survey (see Appendix) and was addressed to the Director of Pupil Services in each system who then passed it on to be answered. (The largest number of respondents were those responsible for special education). All the school systems answered, some in great detail.

3. Limitations

- the survey was intentionally not focused or precise, but broad in scope. It was exploratory in an effort to provide an overview that could identify areas for further investigation in specific areas. Therefore, there was great variability in response. It did, however, offer an opportunity to freely express concerns and identify major issues seen as important by those in the system.
- the informants and their positions were not identified and seemed to vary among the different systems
- because of its open-ended nature, it allowed some to give minimal or only general information.
- because it was open-ended some school systems appear to have omitted some of their activities and procedures.
II Findings and Recommendations

There are 24 local school systems and 24 different ways of providing school services to children and youth with ADHD in Maryland. The survey shows a lack of consistency in policies and procedures for children with ADHD across the state.

A. Fifty percent of the systems did not cite a description or what was used to define a child with ADHD. Others listed the DSM-IV psychiatric manual. Concern was expressed that the definition for schools be translated and oriented towards what were the educational implications of such a condition.

Recommendation: Clarification of who makes the diagnosis and for what purpose. It should be clear that school systems are interested in diagnosis not for the purpose of medical or clinical treatment but for the purpose of providing appropriate educational services so that learning can occur.

B. Confusion was expressed regarding the uses of IDEA and 504 procedures especially with regard to ADHD. School systems are not clear under what domain, 504 or IDEA, ADHD falls and what criteria schools would use to make that determination.

Recommendation: Guidelines are needed to clarify the IDEA and 504 policies and requirements as they pertain to ADHD with decision trees and flow charts if possible.

C. Only four school systems have explicit written policies against staff recommending medication for ADHD. Ten school systems have oral informal policies.

Recommendation: There is a need for a written policy that school personnel not recommend medication. Guidelines for appropriate mechanisms for referral by parents to outside services should be developed.

D. Thirty-three percent did not cite or describe procedures for referral or communication with outside resources for children suspected of having ADHD. A majority of those who answered did not cite procedures that were specific to children with ADHD.

Recommendation: There is need to clarify the options that are acceptable and available for referral. Guidelines are needed for referral and on-going communication with the outside resources, those diagnosing and treating children with ADHD.

E. Thirty percent of the school systems cite the need for one or more specialists in the school knowledgeable about ADHD and its educational implications.

Recommendation: There is a need to identify a person or persons in each school system central office who are knowledgeable and up-to-date regarding ADHD and who would be available as a resource for those in the schools. In addition, each school should have a specialist available who is knowledgeable regarding ADHD and the availability of educational services.
Survey of MD Local School Systems on ADHD

F. Thirty percent of the school systems do not cite teacher/staff development on ADHD and those that do show a wide range of answers some saying it was only offered to special educators or to elementary school teachers. 

**Recommendation:** There is a need for staff development with clarification of its purpose and audience. The Central office resource person knowledgeable regarding ADHD should be responsible for such staff development. Staff development regarding ADHD should be offered to all personnel working with children, elementary and secondary school teachers, specialists, administrators, support services, etc.

G. Fifty percent did not cite parent/family communication. Twenty percent had handouts or specific flyers on ADHD.

**Recommendation:** It would be of value to develop a clear policy regarding the basic information and written materials which can be given to parents regarding ADHD.

H. Forty percent did not cite any monitoring of children diagnosed with ADHD. Others made general statements relating it to special education or 504 monitoring procedures.

**Recommendation:** Clear monitoring responsibilities should be defined and outlined with tracking of children with ADHD.

I. Issues, comments, and concerns were expressed in areas of . . .

a. Assessment and diagnosis

Is there any agreement or consensus on how to identify ADHD? What is a good diagnostic evaluation and how can it be judged? How does a school system make use of a diagnostic report done by outside specialists? Who, if anyone, in the school system is qualified to identify possible ADHD? How is it identified?

b. Service delivery and coordination

How does one coordinate with physicians and others? There is a need for more effective mechanisms for implementing recommendation. Some respondents noted that school staff sometimes can't or won't make the accommodations that are needed to help children with ADHD.

c. Resource issues

Where does one get accurate information? How do we get enough and appropriate support staff? What referral resources are available to direct parents to appropriate community facilities.

d. Accountability

Is it possible to get a standard procedure for collecting data? How does one get data on the progress of children with ADHD? What data needs to be collected and how does one build in accountability? How will the data collected be used?
Selected Resources
SELECTED RESOURCES

Additional sources of help are listed here and are organized in these categories:

- Resources for Kids (Also see Videos & Newsletters categories.)
- Resources for Teens and Adults
- Resources for Parents
- Resources for Teachers (Also see Video category.)
- Resources for Professionals
- Additional Resources
  - Books
  - Legal Resources
  - Videos
  - ADD Resource Catalogues
  - Newsletters
  - Computer Software Resources
  - Internet Resources
  - Organizations/Support Groups
  - Advocacy Resources

RESOURCES FOR KIDS


RESOURCES FOR TEENS AND ADULTS


RESOURCES FOR PARENTS

BOOKS

Garber, S. W. et al. If Your Child is Hyperactive, Inattentive, Impulsive, Distractible....New York.
RESOURCES FOR PARENTS (Continued)

BOOKS

RESOURCES FOR TEACHERS
RESOURCES FOR TEACHERS - continued


PROFESSIONAL RESOURCES


ADDITIONAL RESOURCES

LEGAL RESOURCES

VIDEOS (THOSE WITH *ARE FOR KIDS; THOSE WITH ** ARE FOR TEACHERS)
VIDEOS - Continued

**Goldstein, S. and Goldstein, M. Educating Inattentive Children.** Salt Lake City: Neurology Learning and Behavior Center, 1990.
(1-800-682-3528)

ADD RESOURCE CATALOGUES

**ADD Books**
P. O. Box 157
Dexter, MI 48130
(313)662-2778

**ADD Clinic**
Resources for Parents
983 Howard Avenue
Biloxi, MS 39531
1-800-962-2673

**ADD Discount Books**
312 Riley Circle
Gadsden, AL 35901

**ADD Warehouse**
300 Northwest 70th Avenue
Suite 102
Plantation, FL 33317
(305-792-8944)

**Attention Deficit Resources Center**
1344 Johnson Ferry Road
Suite 14
Marietta, GA 30068

**National Professional Resources, Inc.**
Dept. C95, 25 South Regent Street
Port Chester, NY 10573
914-937-8879, FAX: 914-937-9327

**The FRIC Clearinghouse on Disabilities and Gifted Education**
The Council for Exceptional Children
1920 Association Drive
Reston, Virginia 20191-1589
1-800-328-0272
TTY 703/264-9449
E-mail: ericec@cec.sped.org

**NEWSLETTERS (THOSE WITH * ARE FOR KIDS)**
**ADD Forum (CompuServe)**
800-524-3388 (Representative 464)

**ADD-ONS**
P. O. Box 675
Frankfort, KY 60423

53
The ADHD Report
Russell Barkley, Editor
Guilford Publications
72 Spring Street
New York, NY 10012
800-365-7006

The ADDed Line
3320 Creek Hollow Drive
Marietta, GA 30062
800-982-4028

ADDult News
c/o Mary Jane Johnson
ADDult Support Network
2620 Ivy Place
Toledo, OH 43613

Advance, a publication of ADDAG
8091 S. Ireland Way
Aurora, CO 80016
303-690-7548

ATTENTION (Magazine)
CH.A.D.D. National Headquarters
8181 Professional Place, Suite 201
Landover, MD 20785
301-306-7070

Attention Please, Newsletter for children with Attention Deficit Disorder
2106 3rd Avenue, N.
Seattle, WA 98109-23905

*BRAKES: The Interactive Newsletter for Kids with ADHD
Magination Press
19 Union Square West
New York, NY 10003

CHADD Newsletters (CHADDER/CHADDER BOX)
CH.A.D.D. National Headquarters
8181 Professional Place, Suite 201
Landover, MD 20785
301-306-7070

Electronic Bulletin Boards
(a) American On-line
(b) Prodigy
(c) Disabilities Forum
(d) ADD Bulletin Bord

HAAD ENOUGH (Bi-Monthly)
HAAD Support Groups
P. O. Box 20563
Roanoke, VA 24018

Kids Getting You Down?
Learning Development Services
3754 Clairemont Drive
San Diego, CA 92117

The Rebus Institute Report
1499 Bayshore Blvd., Suite 146
Burlington, CA 94010

COMPUTER SOFTWARE RESOURCES
ABLEDATA
National Rehabilitation Information Center
Catholic University of America
4407 Eithth St., NE
Washington, D.C. 20017
(202)635-5822

"Following Directions" (Grades 3-6)
Lawrence Productions
1800 S. 35th Street
Galesburg, MI 49053
(800) 645-6564

Kids Works 2
Davidson and Associates
P. O. Box 2961
Torrance, CA 90509 (800)545-7677

Miranker, C. and Elliot, A.
The Computer Museum Guide to the Best Software for Kids

"Test Taking Made Easy" (Grades 2-5)
Lawrence Productions
1800 S. 35th St.
Galesburg, MI 49053
(800)645-6564
INTERNET RESOURCES

One ADD Place
(http://www.greatconnect.com/oneaddplace)
A "Virtual neighborhood" that consolidates information and resources.

ADD Webnet
(http://members.aol.com/addwebney/index.html)
A central directory of links that connects you to sites of individuals or groups that provide information, offer support, or share insights on ADD.

ADD and ADHD Infoline
(http://www.alcasoft.com/add)
Information and resources put together by a family's personal experience with ADD.

ORGANIZATIONS/SUPPORT GROUPS

ADDA (Attention Deficit Disorder Assoc.)
P. O. Box 972
Mentor, OH 44060
(800)487-2282

ADDA (Attention Deficit Disorder Advocacy Group)
8091 South Ireland Way
Aurora, CO 80016
(303)690-7548

ADDIEN (ADDult Information Exchange Network)
P. O. Box 1701
Ann Arbor, MI 48106

ADDult Support Network (for ADD Adults)
Mary Jane Johnson
2620 Ivy Place
Toledo, OH 43613

Adult ADD Association
1225 East Subset Drive, Suite 640
Bellingham, WA 98226-3529
(206) 647-6681

Attention Deficit Information Network (AD-IN)
475 Hillside Avenue
Needham, MA 02194
(617) 455-9895

Professional Group for ADD and Related Disorders (PGARD)
28 Fairview Road
Scarsdale, NY 10583
(914)723-0118

Attention Deficit Resource Center
(Special Focus on ADD Adults)
Lawrence L. McLean, Ph.D., Director
1344 Johnson Ferry Road, Suite 14
Marietta, GA 30068
(800)537-3784

Children with Attention Deficit Disorders (CHADD)
8181 Professional Place, Suite 201
Landover, MD 20785
(301)306-7070

The Council for Exceptional Children
1920 Association Drive
Reston, VA 20191
(800)328-0272

Learning Disabilities Association (LDA)
4156 Library Road
Pittsburgh, PA 15234
(412)341-1515

National Network of Learning Disabled Adults (NNCDA)
808 West 82nd St., F-2
Scottsdale, AZ 85257
ADVOCACY RESOURCES

- Learning Disabilities Association of America (LDA) (PA) (412)341-1515 (State LDA Office and Local LDA Chapter)

- Orton Dyslexia Society (MD) 1-800-222-3123

- National Center for Learning Disabilities (NY) (212) 545-7510

- CH.A.D.D. (Children & Adults with Attention Deficit Disorders) National Office (FL) 1-800-23304050 (Ask for local chapters.)

- TAPP/PTI Office (Technical Assistance for Parent Programs Project/Parent Training & Information Projects) Check with your state or local LDA office or call the Federation for Children with Special Need (MA) (617)482-2915.

- National Association of Protection & Advocacy Systems (legal information & support) (202)408-9514


- NICHCY (National Information Center for Children and Youth with Disabilities (Washington, D.C.) 1-800-695-0285

- ERIC Clearinghouse for Handicapped and Gifted Children, Council for Exceptional Children (VA) (703)264-9474

- Office for Civil Rights (Contact your state LDA or TAPP/PTI Office)

- Local Special Education Attorney

- Local School Psychologist, Personnel and Superintendent
As a result of the work of the members of the Task Force to Study the Uses of Methylphenidate and Other Drugs on School Children additional information regarding Attention Deficit Hyperactivity Disorder (ADHD) and the use of medication to treat ADHD has been gathered. This information and other results of subcommittee work have been compiled in a separate document entitled Task Force to Study the Uses of Methylphenidate and Other Drugs on School Children Report Appendix.

A copy of this document can be obtained by calling the Maryland State Department of Education, Pupil Services Branch at 410-767-0311 or the Maryland Department of Health and Mental Hygiene, Office of Children’s Health at 410-767-4586.