

**CFSAC Education Subcommittee report
June 2004**

Education on CFS and chronic fatiguing illnesses has been targeted as number one priority by the CFSAC; and an 8-member education subcommittee was established. The subcommittee has held internal discussions and correspondence exchanges, reviewed resources (printed, web-based, etc.), and summoned the advice and experience of individuals, patient organizations, professional societies, and governmental agencies to:

- Identify and assess past, existing and novel educational strategies;
- Formulate and encourage involvement at individual and organizational levels;
- Invite ideas with experiential substantiation or high likelihood of success/impact;
- Formulate recommendations for consideration by the full CFSAC committee.

Assessment of CFS and CFS-related education

Successes

There is increased awareness, diagnosis and treatment of fatigue in different contexts, such as cancer and autoimmune disease.

Limitations and challenges

70% of primary care physicians are frustrated with CFS care and challenging patient population (source: survey, CFIDS Association, 2003). Inability of CFS educators to fulfill expectations stems from a series of limitations:

Content/format: Paucity of evidence-based treatment guidelines; limited and partially standardized CFS case definition; and limited study of CFS natural course, epidemiology and nosology.

Attrition or limited impact of CFS educators.

Most literature sources too specialized, general, and/or outdated.

CFS is included under restrictive categories, such as Women's Health.

Most professional societies lack CFS education-targeted programs.

Impact/outreach: Most educational activities are focused on physicians and nurses.

Limited number and variety mix of healthcare professionals reached.

For instance, 10% occupational/physical therapists reached.

Web-based activities seem to have better numerical outreach.

Mostly inexistent outcome assessment of CFS educational activities.

Funding: Limited for needs.

Suggested recommendations:

General

Increase funding through governmental agencies (CDC and HRSA) to address four target areas; specific aims have been outlined for each area:

Content: *Raise contextual awareness and use learned lessons in CFS and other diseases.*

Educate on fatigue as a symptom, on its diagnosis and treatment in chronic fatiguing illnesses; educate on CFS and its peculiarities.

Use lessons from pain, nausea, and other symptoms that were previously under-diagnosed and under-treated in the context of both recognized and poorly understood syndromes in different specialties (i.e., cancer, autoimmunity).

Address and raise awareness about the different populations affected by CFS: pediatric, adults, men and women.

Format: Diversify means and emphasize practicality.

Expand on the use of the worldwide web and other communication means.

Place CFS within appropriate disease categories (i.e., chronic disabling conditions, and not concealed under partially appropriate categories).

Generate practical up-to-date publications and reference guides.

Impact: Increase outreach, recruitment, and follow-up.

Take educational programs to diverse settings nationwide (allied health care and legal professionals, reimbursement and disability specialists, etc.).

Recruit interest/help from professional organizations and high impact journals.

Encourage collection of qualitative/quantitative data on impact of funded activities (i.e., professional mix and numbers reached; practice changes).

Funding: Raise need awareness and encourage involvement of others.

Promote joint ventures with the private sector as well as health care specialty groups.

Specific examples

The aims described above can be achieved through expansion of some of the current programs or implementation of new ones. Suggestions include:

Grants to patient organizations, healthcare professionals, professional societies or, preferentially, partnerships among them to update, develop, and run nationwide and community-based CFS-related educational programs targeted at health care professionals, specialized societies, patients, and/or professional training programs. Past examples include conferences organized with well-respected health care professionals and the support of grass-root organizations.

Grants for distribution of new and existing educational materials at local and nationwide levels (i.e., Physician's Manual for the Diagnosis and Treatment of Chronic Fatigue Syndrome distributed by the State of New Jersey to all its licensed physicians).

Grants for biannual live and/or web-based regional and national workshops or ground rounds on diagnosis, management, and treatment of CFS and other chronic fatiguing illnesses (CFS, cancer-related fatigue, autoimmune disease-related fatigue, fatiguing illnesses secondary to toxic exposures, etc). Past examples are the HRSA, NIH, CDC workshops and their web-based resources.

Grants for education programs aimed at raising awareness for detection and intervention of disability among pediatric and adult CFS patients.

**CFSAC Education Subcommittee full report
June 2004**

1. Action taken by CFSAC Education subcommittee:

Education on CFS and chronic fatiguing illnesses was identified as number one priority by the CFSAC; an education subcommittee was established with the following members (in alphabetical order):

CFSAC members

Nancy Butler
Jane Fitzpatrick
Kenneth Friedman
Nelson Gantz
Roberto Patarca (Chairman)
Staci Stevens

CFSAC ad hoc members

Bill Reeves
Bill Robinson

The subcommittee has held internal discussions, reviewed resources (printed, web-based, etc.), and summoned the advice and experience of individuals, professional organizations, and governmental agencies (see Appendices 1-3) to:

- 1.1 Identify and assess the impact of past and existing strategies and the reasons for their success/failure;
- 1.2 Encourage and formulate specific involvement at individual and organizational levels;
- 1.3 Invite ideas with experiential substantiation or high likelihood of success and impact.
- 1.4 Formulate recommendations for consideration by the full CFSAC committee and help in their implementation by making available through CFSAC website all information gathered.

2. Conclusions from assessment of state of CFS education:

- 2.1 *Successes and limitations of CFS educational activities*
Education in CFS and CFS-related conditions has had its successes and limitations; formidable challenges remain:

Successes

Increased awareness of fatigue as an important symptom to diagnose and treat in different contexts, such as cancer and autoimmune disease, among others.

Limitations and challenges

70% of primary care physicians are frustrated with CFS care and challenging patient population (source: survey, CFIDS Association, 2003).

Inability of CFS educators to fulfill expectations for educating peers and students in health care field:

Limitations in content and format

- Need for evidence-based treatment guidelines; standardization of CFS case definition; and further study of CFS natural course, epidemiology and nosology.
- Attrition or limited impact of CFS educators (for one numerical assessment example see Appendix 4).
- Most literature sources too specialized, too general, inconsistent, and/or outdated (examples in Appendix 5).
- CFS is not included in some governmental sites under restrictive categories, such as Women's Health

Limited outreach of educational activities:

- Most educational activities are focused on physicians and nurses (Appendix 6).
- Need to increase number and variety mix of healthcare professionals reached. For instance, 10% occupational/physical therapists reached.
- Web-based educational activities seem to have better numerical outreach (for instance, see Appendix 7).

Limited and in many cases nonexistent appropriate outcome assessment of CFS-related educational activities.

Limited funding for CFS education.

2.2 *Target areas identified*

Four target areas have been identified and specific aims have been outlined for each area:

2.2.1 *Content*

Aim: Raise contextual awareness and use learned lessons. Educate on fatigue as a symptom, on its diagnosis and treatment in chronic fatiguing illnesses, and on CFS and its peculiarities. Use lessons from pain, nausea, and other symptoms that were previously under-diagnosed and under-treated in the context of both recognized and poorly understood syndromes in different specialties (cancer, autoimmune disease, etc.)

2.2.2 *Impact*

Aim: Increase outreach, recruitment, and follow-up.

Take educational programs to diverse settings nationwide (school nurses and teachers, healthcare/reimbursement specialists, legal, etc.).

Recruit interest/help from professional organizations and high impact journals.

Implement means to collect qualitative/quantitative data on impact of funded activities.

2.2.3 *Format*

Aim: Diversify means and emphasize practicality.

Expand on the use of the worldwide web and other information communication means. Properly place CFS within web sites (i.e., not only under Women's Health or concealed under another category).

Generate practical publications and reference guides.

2.2.4 *Funding*

Aim: Raise need awareness and increase level of funding.

Involve both private and public sectors as well as diverse specialties.

Fund both national and regional groups.

3. **Recommendations:**

3.1 *General*

Increase funding through governmental agencies (CDC and HRSA) to address the content, impact and format limitations of current activities by:

expanding current activities beyond their current impact realm;

developing and implementing new educational programs, services and resources for both healthcare professionals and patients.

Grantees must provide outcomes assessment for funded activities (surveys and other instruments and means; for example incorporate electronic surveys, such as that exemplified in <http://www.zoomerang.com/survey.zgi?p=UOWPRCSCJ>).

Educational activities must address the different populations affected by CFS: pediatric, adults, men and women.

3.2 *Specific*

- Grants to patient organizations, healthcare professionals, professional societies or partnerships among them to update, develop, and run nationwide and community-based CFS-related educational programs targeted at local doctors, specialized societies, patients, and professional training programs.

Example: Lucinda Bateman, MD in Utah. Publicized through clinics and with the help of patients and patient organizations. Impact: Attendance for this CFS/FM conference in 2003: 250 patients and 150 healthcare providers. Of the 150 healthcare providers, 45 were physicians; the rest allied healthcare professionals. The next conference in May 2004 is projecting 400-500 patients/public and 200 providers from UT. Conference success is attributed to the following:

- The conference is organized by a well-respected physician with strong ties to the university;
- There is co-sponsorship between the Organization for Fatigue and Fibromyalgia Research (OFFER) and the CME provider, which is the largest private health insurance company in UT;
- There is well-organized grassroots support from the community and patients.

Example: Renee Taylor's, PhD (University of Illinois in Chicago) multidisciplinary course on fatiguing conditions and disability.

Example: Elizabeth McConn (Youth Education Committee, NJCFSA) "Our main purpose is to offer support to parents and their CFS diagnosed child or adolescent and to provide them with educational materials on pediatric CFS. Our committee is also dedicated to increasing awareness of CFS in children and disseminating reliable information to schools, pediatricians and the general public on the seriousness of chronic fatigue syndrome in young people."

- Grants for distribution of new and existing educational materials at a local and nationwide level.

Example: Physician's Manual for the Diagnosis and Treatment of Chronic Fatigue Syndrome distributed by the State of New Jersey to all its licensed physicians (see appendix 10 for comment by Dr. Kenneth Friedman).

- Grants for biannual live and/or web-based regional and national workshops or ground rounds on diagnosis, management, and treatment of CFS and other chronic fatiguing illnesses (CFS, cancer-related fatigue, autoimmune disease-related fatigue, fatiguing illness as a reflection of toxic exposures, etc).

Example: HRSA, NIH, CDC workshops and their web-based resources.

- Grants for education programs aimed at raising awareness for detection and intervention of disability among pediatric and adult CFS patients.

Example: Debra Price-Ellingstad (U.S. Department of Education's Office of Special Education and Rehabilitation Services) forwarded two policy

letters (appendices 8 and 9) as examples of how a child with CFS would be eligible for special education and related services under IDEA.

Appendix 1

List of professional societies, government agencies, individuals and patient organizations contacted in gathering of data, experiences and ideas.

Professional societies

American Medical Association (AMA)

Michael D. Maves, M.D.; Executive Vice President
515 North State Street
Chicago, Illinois 60610
Phone: 312-464-4000
Fax: 312-464-4184
E-mail: michael_maves@ama-assn.org

Association of American Medical Colleges (AAMC)

Michael E. Whitcomb, M.D.
Senior Vice President for Medical Education
2450 N Street, N.W.
Washington, D.C. 20037-1126
Phone: 202-828-0505
Fax: 202-838-1125
E-mail: whitcomb@aamc.org
Website: www.aamc.org

American Dental Association (ADA)

James B. Bramson, D.D.S
Executive Director
211 East Chicago Avenue
Chicago, Illinois 60611-2616
Phone: 312-440-2700
Fax: 312-440-7488

American Dental Education Association (ADEA)

Richard W. Valachovic, DMD, PhD, MPH; Executive Director
1625 Massachusetts Avenue, N.W., Suite 600
Washington, DC 20036-2212
Phone: 202-667-9433
Fax: 202-667-0642

American Osteopathic Association (AOA)

Douglas O. Woods, DO, PhD, President
1090 Vermont Ave. N.W., Suite 510
Washington, DC 20005
Toll-free phone: (800) 962-9008

General phone: (202) 414-0140

Fax: (202) 544-3525

American Physical Therapy Association (APTA)

Jody Gandy, PT, Ph

Director of Education

1111 N. Fairfax St. Alexandria, VA 22314

Phone : 800-999-2782 Ext. 3203

American Occupational Therapy Association (AOTA)

Janie Scott

4720 Montgomery Lane, P.O. Box 31220

Bethesda, MD 20024-1220

Phone: 301-652-2682

American Psychological Association (APA)

Brennan Harmuth

Manager of Continuing Education

750 1st St. NE

Washington, DC 20002

Phone: 202-336-5994

National Association of School Nurses (NASN)

Janis Hootman, RN, PhD, NCSN

President (nasn@nasn.org; Hoot@teleport.com)

Sue Will, RN, PHN, LSN, BS, MPH

President-Elect

Western office

1416 Park Street, Suite A

Castle Rock, CO 80109

Phone: 866-627-676; 303-663-2329; 303-663-0403

Eastern Office

163 U.S. Route #1

P.O. Box 1300

Scarborough, ME 04070-1300

Phone: 877-627-6476; 207-883-2117; 207-883-2683

American College of Physicians (ACP)

Headquarters

190 North Independence Mall West

Philadelphia, PA 19106-1572

Washington Office

2011 Pennsylvania Avenue NW, Suite 800

Washington, DC 20006-1837
Phone: 202-261-4500 or 800-338-2746

American Association of Colleges of Osteopathic Medicine (AACOM)
Per Dr. Don Weaver, Dr. Doug Wood from the AOA
is the same contact for this association.

American Academy of Family Physicians (AAFP)
P.O. Box 11210
Shawnee Mission, KS 66207-1210
Toll free: 800-274-2237
Local: 913-906-6000

American Academy of Nurse Practitioners (AANP)
Jan Towers, PhD, NP-C, CRNP, FAANP
Director of Health Policy
Office of Health Policy Contact Information
American Academy of Nurse Practitioners
Office of Health Policy
PO Box 40130
Washington, DC 20016
E-mail: dcoffice@aanp.org

American College of Rheumatology (ACR)
1800 Century Place, Suite 250
Atlanta, GA 30345-4300
Phone: 404-633-3777
Fax: 404-633-1870

American Academy of Neurology (AAN)
1080 Montreal Avenue
Saint Paul, MN 55116
Phone: 800-879-1960 or 651-695-2717
Fax: 651-695-2791
E-mail: memberservices@aan.com

American Academy of Physician Assistants (AAPA)
950 North Washington Street
Alexandria, VA 22314-1552
Phone: 703-836-2272
Fax: 703-684-1924
E-mail: aapa@aapa.org

American College of Sports Medicine (ACSM)

James R. Whitehead
Executive Vice President
PO Box 1440
Indianapolis, IN 46206
Phone: 317-637-9200 Ext. 144
E-mail: jwhitehead@acsm.org

National Association of Social Workers (NASW)

Ms. Winnie Reilly, Continuing Education
750 First Street, NE, Suite 700
Washington, DC 20002-4241

American Psychiatric Association (APA)

1000 Wilson Boulevard, Suite 1825
Arlington, VA 22209-3901
Phone: 703-907-7300
E-mail: apa@psych.org

American Speech – Language – Hearing Association

10801 Rockville Pike
Rockville, MD 20852
Phone: (Professionals/Students) 800-498-2071
Phone: (Public) 800-638-8255

American Association of Clinical Endocrinologists (AACE)

1000 Riverside Avenue, Suite 205
Jacksonville, FL 32204
Phone: 904-353-7878
Fax: 904-353-8185

American College Health Association (ACHA)

Executive Director
P.O. Box 28937
Baltimore, MD 21240-8937
410-859-1500 (Voice)
410-859-1510 (Fax)

American School Health Association (ASHA)

President
David K. Lohrmann, PhD, CHES, FASHA
Indiana University
Dept. of Applied Health Science / HPER Bldg. 116

Bloomington, IN 47405-4801
dlohrman@indiana.edu

Council on Chiropractic Education (CCE)

Martha S. O'Connor, Ph.D., Executive Vice President
8049 North 85th Way
Scottsdale, Arizona 85258-4321
Telephone: 480-443-8877
Fax: 480-483-7333
E-Mail: cce@cce-usa.org
Website: www.cce-usa.org

Acupuncturists, Somnologists, Massage therapists, Nutritionists, Physicians in student health centers.

Government agencies

U.S. Department of Education
U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
Human Resources and Services Administration

Individuals and Patient Organizations

Lucinda Bateman, MD
Fatigue Consultation Clinic
1002 E South Temple (Ste 408)
Salt Lake City, UT 84102

Renee Taylor, PhD
Associate Professor
University of Illinois at Chicago
Department of Occupational Therapy
College of Applied Health Sciences
1919 West Taylor Street
Chicago, IL 60612-7250

Debra Price-Ellingstad
Department of Education's Office of Special Education and Rehabilitation Services,
telephone at 202-260-2121, e-mail at: debra.price-ellingstad@ed.gov

Kim McCleary (CFIDS Association)

Jill McLaughlin

Jon Sterling (NJCFSA)

Elizabeth McConn (Youth Education Committee, NJCFSA)

Michael Glick, DD Chairman of Diagnostic Sciences, New Jersey Dental School

Dr. Adam Perlman (Institute of Complimentary and Alternative Medicine)
perlmaad@umdnj.edu

Appendix 2

Letter sent to professional societies for gathering of data, experiences and ideas.

Dear (ORGANIZATION),

Recent studies suggest that there are 800,000 chronic fatigue syndrome (CFS) patients within the United States. More complete epidemiological studies currently being done by the Centers for Disease Control and Prevention may increase that estimate. The cost of CFS is placed in the billions of dollars secondary to lost productivity and healthcare expenses. For these reasons CFS is a national health concern.

In response to this concern, the Department of Health and Human Services has impaneled a federal advisory committee, the Chronic Fatigue Syndrome Advisory Committee (CFSAC). This advisory committee's purpose is to make recommendations to the Secretary of Health regarding appropriate actions to be taken by the Federal Government to address the CFS healthcare challenge. The CFSAC meets with representatives of the Centers for Disease Control and Prevention, the National Institutes of Health, the Social Security Administration, the Food and Drug Administration and the Human Resources and Services Administration who are involved in government programs dealing with CFS.

The Education Subcommittee of the CFSAC calls upon the (ORGANIZATION) to work with us to determine the tools and methods needed to provide effective and comprehensive medical care to patients with CFS. As part of this goal, the CFSAC has established an Education Subcommittee to assist the full committee with the development of recommendations as regards CFS-specific educational activities. To this end, the Education Subcommittee is gathering information, conducting research, and analyzing issues and facts relevant to CFS-specific educational activities. The subcommittee will also report to the CFSAC and provide recommendations for the CFSAC's deliberation.

The CFSAC Education Subcommittee requests (ORGANIZATION) assistance in gathering information on what health care organizations are doing to educate their members about CFS. Information that would be helpful includes:

- Specific information on CFS available to (ORGANIZATION) member and affiliates
- The number of articles appearing in (ORGANIZATION) literature that includes information on CFS
- The number of presentations that have included information on CFS at national meetings
- Specific data regarding recommended treatment procedures
- The reimbursement codes recommended for (professionals) to use when treating CFS patients

- (ORGANIZATION) curricula hours spent on CFS

Any information provided by the (ORGANIZATION) will be useful to the subcommittee. If there is information on CFS that the (ORGANIZATION) would find useful, please let us know and we will attempt to make it available. Feel free to contact the CFSAC Education subcommittee at cfsac@osophs.dhhs.gov
Websites with information on CFS are listed below.

It would be helpful if the CFSAC Education Subcommittee could hear from you by June 1st. Thank you for your assistance.

Sincerely,

Roberto Patarca, M.D., Ph.D., HCLD
Chairman, Education Subcommittee of the CFSAC

HHS, CFSAC or its subcommittees do not endorse any organization whose Web address is listed below; their listing is for informational purposes only.

CFSAC <http://www.hhs.gov/advcomcfs>

CFIDS Association www.cfids.org

American Association for CFS www.aacfs.org

CDC <http://cdc.gov/ncidod/diseases/cfs/program-updates/cfs-update-031703.htm>

NIH <http://www.niaid.nih.gov/factsheets/cfs.htm>

Appendix 3

Replies from professional societies.

AAMC

From: Michael Whitcomb [mailto:mwhitcomb@aamc.org]
Sent: Monday, May 17, 2004 12:17 PM
To: CFSAC
Subject: May 5 letter

Dr. Patarca -

I don't think we have access to any of the information your identified in your letter. Feel free to call if you would like to discuss in more detail -

American
Dental
Association



Office of the Executive Director
211 East Chicago Avenue
Chicago, Illinois 60611-2678
(312) 440-2500
Fax (312) 440-7488
www.ada.org

May 19, 2004

Dr. Roberto Patarca
Chairman, Education Subcommittee of the CFSAC
Department of Health & Human Services

Dear Doctor Patarca:

Thank you for your letter dated May 5, 2004 that called upon the American Dental Association (ADA) to work with the Chronic Fatigue Syndrome Advisory Committee (CFSAC) to identify resources available to health care professionals in the treatment of patients with CFS.

To specifically address the question posed by the CFSAC Education Subcommittee, the ADA does not currently have information available to members on the topic of CFS. However, the ADA is the premier source of information on oral health; and, as such, is eager to provide the dental community with information relevant to the provision of oral health care.

Oral health conditions that have been associated with CFS are: Sjogren's syndrome, temporomandibular disorders and myofascial pain syndrome. In addition, medications used in the treatment of CFS may have an impact on oral health (e.g. xerostomia). For these reasons, the dental community would benefit from receiving information on CFS.

Through its Council on Scientific Affairs, the ADA will work to develop educational information for dissemination to the dental community. The Association looks forward to learning of the advisory committee's recommendations for addressing this healthcare challenge. Thank you for bringing this important issue to the attention of the ADA.

Sincerely,


James B. Bramson, D.D.S.
Executive Director

JBB:mmg

cc: Ms. Mary Logan, chief operating officer, ADA
Dr. Daniel M. Meyer, associate executive director, Division of Science

Replies from patient organizations

Subject: Education recommendations
From: Jill McLaughlin <jillmclaughlin@comcast.net>
Date: Fri, May 21, 2004 3:59 pm
To: <rpatarca@pol.net>, <cfsac@osophs.dhhs.gov>,
"Fields, Larry E (HHS/OS)" <LEFields@osophs.dhhs.gov>,
<dbell005@rochester.rr.com>

Differentiate between physician/health profession education and public education/awareness. The incorporation or blurring of these may cut corners but usually ends up being less effective - for both.

Review CFS info on gov't websites and publications (CDC patient education booklet, NIH or ?NIAID fact sheet, FAQ's etc.) - some is outdated/inconsistent, particularly prevalence figures. Educational information that the government disseminates is of great concern to patients.

Review CDC/CFIDS Association of America (CAA) collaborative education/adventure - content/cost/marketing/oversight.

Children's issues

Children's issues should be a high priority. Pediatricians should be targeted specifically as the illness is even less likely to be recognized in children. [A pediatric definition is necessary as children do not present the same as adults.]

Develop material to educate (alert) school staff/nurses. Given the lack of recognition/awareness within the medical community, school personnel are on the front lines and often are first to realize that something is wrong. (Otherwise, without proper recognition, children are labeled and dismissed as school phobic, depressed or lazy. From personal experience, given the overall state of knowledge (or lack thereof), interactions with the schools are met with little more than having attendance sheets and rank books shoved in your face as reminders of the "problem," i.e., frequent absences. Without a diagnosis, it is then viewed as the parent's fault. Subsequent charges of truancy or even Munchausen Syndrome by Proxy, referrals to social service agencies, and litigation are not uncommon. Children have been removed from the home and placed in foster care.)

Recommend that the Dept. of Education set guidelines to accommodate children with the illness - both school accommodations/curriculum modifications and home tutoring/distance learning. This has been a greater nightmare for many than the illness itself. And the concern still remains that no one on the committee has had young children with

the illness and thus has had no direct understanding or experience with the problems that they face - academically/socially/emotionally.

Funding recommendations

Provide the means for underwriting expenses of local groups, which could expedite the work of regional conferences. It is at the regional area where the MDs and health care workers are, so that is the place to do much of the training.

Provide funding to underwrite people to lecture or put on workshops at professional association meetings sponsored by medical societies. Many would be willing to attend and organize such events if there were funds available to defray costs.

Focus on centers of excellence. There should be several around the country. If they were established, as they are for cancer and other diseases, state of the art care could be provided and these centers themselves could then also provide the capacity to train an entire new generation of health care workers. Many have expressed interest in this

and would love to be involved. Other countries, such as Great Britain, have spent millions on setting up a network of providers for people with

CFS. We have not, and that needs to change. We particularly need services for the homebound and to include provisions to allow people to go into patients homes and provide medical care and services and support, we need resources to develop programming for people who are home-bound, we need funding for local people to get resources to develop

community specific programming. This could be funded by the CDC, as with

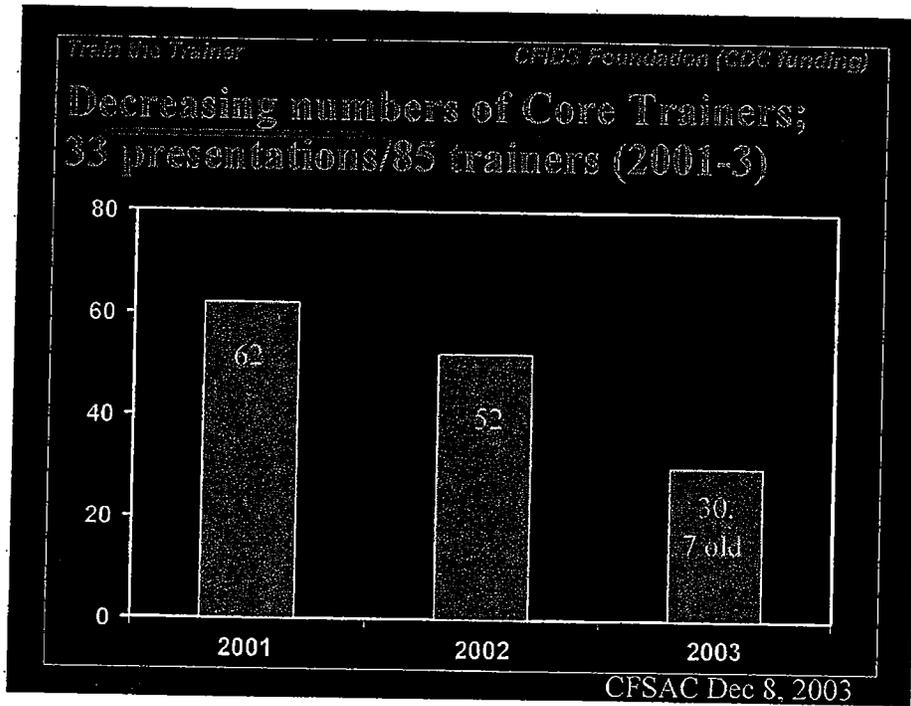
other areas such as tobacco and injury prevention and AIDS, the CDC does

this type of work.

Past education efforts have been less than successful, as Dr. Patarca's presentation to the committee attested. Significant amounts of federal money have gone to the CAA for education by CDC and HRSA, with less than optimal results. The most recent CDC/CAA "education" venture does not seem to be a judicious use of time or money. Efforts must be significantly increased and more focused, and more attention and oversight needs to be put on these issues.

Jill

Appendix 4
Example of numerical attrition of CFS educators.



Appendix 5

Multiple organizations

Bibliography and information

Outdated, too specialized or too general

- AACFS:
 - Bibliography current as of October 1997
 - <http://www.aacfs.or/html/educmatertoc.htm>
- Journal of Chronic Fatigue Syndrome:
 - Literature in Review sections
 - (last in vol. 11, no. 2, 2003; available online)
- General information:
 - NIH:
 - <http://www.niaid.nih.gov/factsheets/cfs.htm>
 - CFIDS F, CDC, AACFS, etc.
 - Newsletters and web sites

CFSAC Dec 8, 2003

Appendix 6

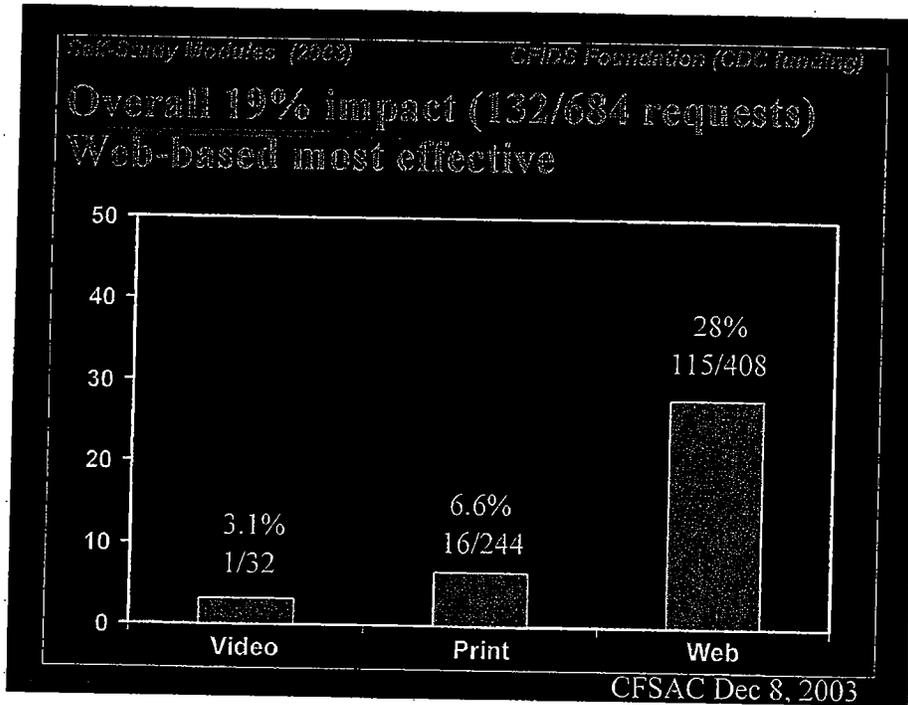
Multiple organizations

Conferences and meetings Mainly oriented to CFS specialists/PCPs

- CFIDS F (with CDC funding):
 - CFS programs in major conferences:
 - 4 in 2002 (2 AACFS, 1 NPACE, 1 NMA)
 - 2 in 2003 (2 ground rounds in Oregon)
 - Modular displays: 6 national conferences
- AACFS:
 - Biennial Research, Clinical and Patient Conference
 - Biennial Patient Symposia
- NIH:
 - NIH CFS State-of-the Science Consultation: 2000, 2003
 - <http://www.niaid.nih.gov/dmid/meetings/cfsreport.htm>
- HRSA:
 - Satellite Conference: 1997

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Appendix 7



Appendix 8

**Policy letter forwarded by Debra Price-Ellingstad (U.S. Department of Education)
on disability issues related to children with CFS.**

21 IDELR 572

21 LRP 2759

Letter to Fazio

Office of Special Education Programs

April 26, 1994

Related Index Numbers

175.040 Eligibility Criteria, Other Health Impairment

345.015 Other Health Impairment, Other Conditions

Case Summary

Are children who have Chronic Fatigue Syndrome (CFS), also known as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), eligible for special education and related services under Part B of the IDEA under "other health impaired", or another category of disability?

A child with Chronic Fatigue Syndrome (CFS), also known as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), will be eligible for special education and related services as other health impaired (OHI) if the participants of a multidisciplinary team determine the following: that the child has "limited strength, vitality or alertness, due to a chronic or acute health problem," such as CFS; the child's educational performance is adversely affected because of the limited strength, vitality or alertness; and the child requires special education and related services. A child with CFS could also be eligible under another category of disability within Part B if the child is determined to meet the criteria for that disability.

Judge / Administrative Officer

Thomas Hehir, Director

Full Text

Honorable Vic Fazio

House of Representatives

Washington, DC 20515

Text of Inquiry

I am writing on behalf of a constituent who has a child diagnosed with Chronic Fatigue Syndrome (CFS) and who is working with []. local school district to develop a plan for home instruction and educational accommodation of [] child's disabilities.

My constituent has requested that I ask the Department of Education to *clarify whether children who have CFS are eligible for special education services*. Specifically:

Would a child diagnosed with Chronic Fatigue Syndrome (CFS), also known as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) be eligible for special education and related services under Part B of the Individuals with Disabilities Education Act under "other health impaired," as defined by 34 CFR 300.7(b)(8), or under another category of disability?

Any assistance that you can provide in responding to my constituent will be greatly appreciated. Thank you, in advance, for your help with this matter.

Text of Response

This is in response to your letter to Assistant Secretary for Legislation and Congressional Affairs Kay Casstevens concerning children with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) or Chronic Fatigue Syndrome (CFS). Your letter has been referred to the Office of Special Education Programs for my response. Specifically, you ask the following question:

Would a child diagnosed with [CFIDS] be eligible for special education and related services under Part B of the Individuals with Disabilities Education Act [Part B] under "other health impaired" as defined by 34 CFR [§] 300.7(b)(8), or under another category of disability?

As you know, in order to be eligible for services under Part B, a child must be evaluated as having one or more of thirteen disabilities, and because of those disabilities need special education and related services. 34 CFR § 300.7(a). The disability "other health impairment" (OHI) is defined as:

. . . having limited strength, vitality or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes that adversely affects a child's educational performance.

34 CFR § 300.7(b)(8).

The list of chronic or acute health problems included within the definition of "other health impairment" in the Part B regulations is not exhaustive. The term includes chronic or acute impairments that result in limited strength, vitality, or alertness and adversely affect educational performance. In evaluating a child with CFIDS to determine eligibility for special education and related services as OHI, the participants on the multidisciplinary team must determine (1) whether the child has "limited strength, vitality or alertness, due to a chronic or acute health problem," such as CFIDS; (2) whether the child's educational performance is adversely affected because of the limited strength, vitality or alertness; and (3) whether the child requires special education and related services. *See* 34 CFR §§ 300.7(b)(8) and 300.532.

A child with CFIDS or CFS could also be eligible for services under Part B if the child is evaluated and determined to meet the eligibility criteria for any of the other disability categories under Part B, as defined at 34 CFR § 300.7(b)(1)-(13). This determination must be made by the participants on the child's multidisciplinary team, which must include at least one teacher or other specialist with knowledge in the area of suspected disability. 34 CFR § 300.532(e).

Please note that under Part B, a child's entitlement is not to a specific disability classification or label, but to a free appropriate public education. Thus, if a child with CFIDS or CFS is determined eligible for special education and related services, the responsible public agency must ensure that the child receives a program of instruction and support services appropriate to meet his or her special education and related services needs.

I hope that this information is helpful to you. If I may be of further assistance, please let me know.

Thomas Hehir

Director

Office of Special Education Programs

Regulations Cited

34 CFR 300.7(b)(8)

34 CFR 300.7(a)

34 CFR 300.532

34 CFR 300.7(b)(1)-(13)

34 CFR 300.532(e)

Appendix 9

Policy letter forwarded by Debra Price-Ellingstad (U.S. Department of Education) on disability issues related to children with Asperger's syndrome as an example applicable to children with CFS.

Ms. Michele Williams
Education Consultant and Advocate
8004 S.W. 198 Terrace
Miami, Florida 33189-2116

Dear Ms. Williams:

This is in response to your letter written to Dr. Thomas Hehir, former director of the Office of Special Education Programs (OSEP), in which you ask a number of questions regarding the requirements of Part B of the Individuals with Disabilities Education Act (Part B) that apply to the education of children with Asperger's Syndrome, which you describe as "a form of high functioning autism."

Based on telephone conversations with a member of my staff, it is our understanding that you would like OSEP to respond to the questions that follow, even though many of the questions you are now raising have been addressed in OSEP's prior responses to your inquiries. Due to the large number of questions in your letter, we have not restated each question individually, but instead have summarized the questions and have provided responses in topic areas. An explanation of the requirements of Part B that are relevant to your inquiry follows.

Please note that Part B is the Federal law that OSEP administers. However, some of the questions you have raised relate to the requirements of Federal laws other than Part B. Specifically, the Office for Civil Rights (OCR) enforces two Federal laws, Section 504 of the Rehabilitation Act of 1973 (Section 504), as it applies to programs and activities receiving Federal financial assistance, and Title II of the Americans With Disabilities Act of 1990, (Title II) as it applies to school districts and public libraries, regardless of receipt of Federal funds. Both Section 504 and Title II prohibit discrimination on the basis of disability and require the provision of appropriate educational services to students with disabilities subject to the protections of those laws. You will need to address questions regarding the application of Section 504 and Title II to the areas noted in this response directly to OCR by contacting the OCR official whose name and address appear below:

Gary Walker
Office for Civil Rights, Atlanta Office
U.S. Department of Education
61 Forsyth St. S.W., Suite 19T70
Atlanta, GA 30303-3104
Telephone: (404) 562-6350; TDD (404) 331-7236

Fax: (404) 562-6455
Email: OCR_Atlanta@ed.gov

Identification and Evaluation of Students with Asperger's Syndrome

Questions 1 through 4 of your letter seek clarification regarding a school district's responsibility to identify and evaluate children suspected of having Asperger's Syndrome, whether Asperger's Syndrome is considered a disability under Part B, and if so, the disability designation under Part B that would be used for eligible children. Part B contains requirements for State and local educational agencies (SEAs and LEAs) to locate, identify, and evaluate children suspected of having disabilities under Part B who need special education and related services and to make a free appropriate public education (FAPE) available to eligible children. 34 CFR §§300.125 and 300.220. Let me emphasize that whether a child with Asperger's Syndrome or any other identified impairment would be eligible for services under Part B is a determination that must be made on an individual basis in light of the child's unique educational needs. The entitlement under Part B is to FAPE, and not to a particular label. In addition, a school district is not required by Part B to evaluate a child if the school district does not suspect that the child has a disability. In that instance, the school district must notify the parents under 34 CFR §300.503(a) of their refusal to evaluate the child and the parent's right to initiate an impartial due process hearing to challenge the refusal.

The regulations define the term "child with a disability" in relevant part as follows:

(a) General. (1) As used in this part, the term *child with a disability* means a child evaluated in accordance with §§300.530-300.536 as having mental retardation, a hearing impairment including deafness, a speech or language impairment, a visual impairment including blindness, serious emotional disturbance (hereafter referred to as emotional disturbance), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services.

34 CFR §300.7(a)(1)

With respect to children aged 3 through 9 experiencing developmental delays, paragraph (b) of §300.7 provides as follows:

The term *child with a disability* for children aged 3 through 9 may, at the discretion of the State and LEA and in accordance with §300.313, include a child-

(1) Who is experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and

(2) Who, by reason thereof, needs special education and related services.

34 CFR §300.7(b)(1)-(2).

Your letter indicates that Asperger's Syndrome is a form of "autism," and Part B contains a definition of "autism" at 34 CFR §300.7(c)(1). Therefore, if a child with Asperger's Syndrome meets the criteria in the Part B definition of "autism" at 34 CFR §300.7(c)(1), a child with that condition could be found eligible for services under Part B. Because a child with this condition could be found eligible for services under Part B under one of the existing disability categories, we do not believe it necessary to address the question of whether Asperger's Syndrome should be treated in the same manner as attention deficit disorder and attention deficit hyperactivity disorder, the examples of which were added to the "other health impairment" definition at 34 CFR §300.7(c)(9). The conditions listed in the Part B definition of "other health impairment" are examples of conditions that could render a child eligible under that category. Regardless of whether Asperger's Syndrome is identified as a condition that could render a child "other health impaired," we do not believe it would be inconsistent with Part B for a State to permit school districts to evaluate children with Asperger's Syndrome to determine whether they could be considered other health impaired. In addition, children with Asperger's Syndrome aged 3 through 9 can be classified as developmentally delayed if the State and LEA utilize that classification, and if the child's condition meets the criteria in the definition of developmental delay adopted by the State.

The Individuals with Disabilities Education Act Amendments of 1997 (IDEA '97) further clarify that "[n]othing in the Act requires that a child be classified by their disability so long as each child who has a disability listed in §300.7 and who, by reason of that disability, needs special education and related services, is regarded as a child with a disability under Part B of the Act." 34 CFR §300.125(d). However, to satisfy the Part B definition of "child with a disability," a child must be in need of special education and related services. If the only service that a child needs is a related service, such as speech pathology, occupational therapy or physical therapy, that service could be considered special education, if the service consists of specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, and "is considered special education rather than a related service under State standards." 34 CFR §300.26(a)(2)(i) (emphasis added).

Before the initial provision of special education and related services under Part B to a child with a disability, a full and individual initial evaluation must be conducted in accordance with the requirements of 34 CFR §§300.532-300.533 of the Part B regulations. Among these requirements is that a variety of assessment tools and strategies must be used to gather relevant functional and developmental information about the child, including information provided by the parent, and information related to enabling the child to be involved and progress in the general curriculum, and for preschool children, to participate in appropriate activities. This information will assist in determining whether the child is a child with a disability under §300.7 and with the content of the child's individualized education program (IEP). 34 CFR §300.532(b). The child must be "assessed in all areas related to the suspected disability, including, if appropriate, health, vision, hearing, social and emotional status, general intelligence,

academic performance, communicative status, and motor abilities.” 34 CFR §300.532(g). Under Part B, each child’s eligibility determination must be made after the completion of the administration of tests and other evaluation materials by a group of qualified professionals, including the child’s parent. 34 CFR §300.534(a).

Provision of Services for Children with Asperger’s Syndrome in the Least Restrictive Environment

Questions 5 through 8 of your inquiry seek clarification relevant to issues regarding the provision of specific services and appropriate placements for children with Asperger’s Syndrome. IDEA ‘97 and the Department’s regulations also underscore that a child found eligible for services under Part B must receive services to address that child’s identified special educational needs. This emphasis is supported by the new requirement at 34 CFR §300.532(b)(1) in the evaluation process, as noted above, that a variety of assessment tools and strategies must be used to gather relevant functional and developmental information about the child. In addition, a child’s evaluation must be “sufficiently comprehensive to identify all of the child’s special education and related services needs, whether or not commonly linked to the disability category in which the child has been classified.” 34 CFR §300.532(h).

Once a child is determined eligible for services under Part B, an IEP must be developed for the child, which contains the instruction and services that form the basis for the child’s placement. 34 CFR §300.535(b). Decisions regarding the provision of services that are appropriate for an individual child must be based on the child’s special education and related services needs, and not on the disability category in which the child is classified. 34 CFR §300.300(a)(3).

IDEA ‘97 focuses each disabled child’s IEP on the child’s involvement and progress in the general curriculum, that is, the same curriculum as for nondisabled students. This is true regardless of whether a child has the behavioral difficulties described in your inquiry. In particular, each child’s IEP must include measurable annual goals, including benchmarks or short-term objectives related to meeting the needs that arise from the child’s disability, to enable the child to be involved and progress in the general curriculum, as well as meeting each of the child’s other educational needs that result from the child’s disability.

The IEP team, which includes the child’s parents and other school officials, determines a child’s program, including, as appropriate, the special education, related services, supplementary aids and services, and program modifications and supports for school personnel to be provided to the child or on behalf of the child. 34 CFR §300.347(a)(1)-(3).

You ask about specific services for children with Asperger’s Syndrome. Part B does not dictate the services to be provided to individual children based solely on the disability category in which the child has been classified. Whether speech pathology or any other related service is required for a particular child with a disability is a determination that

must be made on an individual basis by the child's IEP team. The same is true with respect to social skills training, even though Part B does not identify social skills training as a related service. The related services listed in Part B are examples of related services that could be provided if required to assist a child with a disability to benefit from special education, and this list is not intended to be exhaustive.

There is nothing in Part B that would preclude an IEP team from including in a child's IEP a related service that the team determines is necessary for the child to benefit from special education, even though that service is not specifically mentioned in the statute or the regulations. Conversely, there is nothing in Part B that would require an IEP team to include in a child's IEP any related service, including services listed in Part B, such as speech pathology or occupational therapy, or services not listed in Part B, such as social skills training, based solely on a parent's request for that service, if the IEP team determines that the service is not required to assist the child to benefit from special education.

Once the services determinations are made, the group of persons that makes the placement decision, including the child's parents and other persons knowledgeable about the child and available placement options, must determine the appropriate setting in which required services can be provided. 34 CFR §300.552(a)(1). IDEA '97 also requires that each child's IEP contain an explanation of the extent, if any, to which the child will not be educated and participate with nondisabled children in the regular class and in academic, extracurricular and other nonacademic activities. 34 CFR §300.347(a)(4); Appendix A to 34 CFR Part 300, question 1, published at 64 Fed. Reg. 12470-12471 (Mar. 12, 1999). This means that if a child with a disability is not appropriately included in general curricular and extracurricular activities with his or her nondisabled peers, that lack of participation must be explained in the child's IEP.

The child's placement also is determined in accordance with Part B's least restrictive environment (LRE) requirements at 34 CFR §§300.550-300.554. 34 CFR §300.552(a)(2). LRE means that, to the maximum extent appropriate, children with disabilities must be educated with children who are not disabled, and that "special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily." 34 CFR §300.550(b). These requirements express a strong preference for educating disabled children in regular classes with their nondisabled peers with appropriate supplementary aids and services in the school they would attend if not disabled. The Part B regulations also provide that a child with a disability is not to be removed from education in age-appropriate regular classrooms solely because of needed modifications in the general curriculum. 34 CFR §300.552(e).

Placements must be individually determined based on the unique educational needs and abilities of each disabled child and may not be made based solely on factors such as category of disability, significance of disability, availability of special education and related services, availability of space, configuration of the service delivery system, or

administrative convenience. 34 CFR 300.552; Appendix A to 34 CFR Part 300, question 1, published at 64 Fed. Reg. at 12471.

Behavioral and Discipline Issues

Questions 9 through 11 of your letter concern whether the discipline provisions in Part B can be extended to students with Asperger's Syndrome who may not have been found eligible for special education and related services. It is critical for school officials and parents to respond appropriately and promptly to signs of misconduct when they first appear, since doing so could avoid the need for more drastic measures. We are committed to helping schools respond appropriately to a child's behavior, promoting the use of appropriate behavioral interventions, and increasing the likelihood of success in school and school completion for some of our most at-risk students.

The Part B regulation at 34 CFR §300.527 addresses protections for children not yet eligible for special education and related services. A copy of that section is enclosed for your information. Whether the children described in your inquiry could assert any of the protections under Part B is a determination that would have to be made on an individualized basis in light of the particular facts and circumstances.

For further information about the discipline provisions in Part B, see 34 CFR §§300.520-300.529 as well as the discussion of these provisions in Attachment 1 to the final regulations, published at 64 Fed. Reg. 12406 (Mar. 12, 1999). A detailed discussion of the discipline provisions and some commonly-asked questions and answers is found in the preamble to the final regulations at 64 Fed. Reg. at 12413-12416.

Question 11 of your letter concerns the appropriate setting in which to serve a child with Asperger's Syndrome if the child is exceptionally aggressive and mimics the behaviors of others. Part B specifies a number of special factors which must be considered in IEP development. 34 CFR §300.346(a)(2)(i)-(v). Specifically, if a child with a disability has behavior problems and the child's behavior impedes his or her learning or that of others, the IEP team must consider, if appropriate, whether strategies, including positive behavioral interventions, strategies, and supports are needed to address that behavior. 34 CFR §300.346(a)(2)(i). See responses to questions 5 through 8 above.

Responsibilities of Teachers

Questions 12 through 16 of your inquiry concern teacher responsibilities to children with Asperger's Syndrome under Part B. If a teacher determines that he or she will not have a child with Asperger's Syndrome in the classroom or refuses to implement the child's IEP or Section 504 plan, solely by reason of the Asperger's Syndrome, the teacher's refusal to teach the child in his or her classroom could constitute discrimination on the basis of disability in violation of Federal civil rights laws. As noted above, a child with a disability may not be removed from age-appropriate regular classrooms solely because of needed modifications to the general curriculum for that child. 34 CFR §300.552(e). Under IDEA, lack of adequate personnel or resources does not relieve school districts of

their obligations to make FAPE available to each disabled student in the least restrictive educational setting in which his or her IEP can be implemented. Section 504 and Title II of the ADA prohibit exclusion of a student from an appropriate placement based solely on the student's disability. However, placement in a particular regular class based on the qualifications of a particular teacher is permissible under these laws.

With regard to training, IDEA '97 emphasizes the role of the child's regular education teacher as a member of the IEP team, (if the child is, or may be, participating in the regular education environment). 34 CFR §300.344(a)(2). As an IEP team member, the regular education teacher of the child, in particular, must assist in the determination of appropriate positive behavioral interventions and strategies for the child, and supplementary aids and services, program modifications or supports for school personnel that will be provided for the child, consistent with §300.347(a)(3). In order for the teacher to effectively implement this aspect of the child's IEP, the teacher may need support and assistance to facilitate the child's receipt of an appropriate education in a regular classroom. The child's IEP team should determine whether teacher training should be reflected in the child's IEP, as a program modification and support for school personnel to be provided for the child or on behalf of the child. Input from the child's regular education teacher, as a member of the IEP team, is essential in this process. This training could facilitate the participation in the regular classroom and in other nonacademic and extracurricular services and activities.

Questions 15 and 16 of your letter concern whether students with Asperger's syndrome should be required to participate in field trips, and whether it is permissible for school personnel to exclude students with Asperger's syndrome from required field trips. If these students have been found eligible under Part B, the student's IEP team would determine whether a student with Asperger's Syndrome could be excluded from a required field trip, and, if so, under what circumstances. This is because the student's IEP must contain a statement of the special education and related services and supplementary aids and services to be provided to the child, or on behalf of the child, to be involved and progress in the general curriculum and to participate in extracurricular and other nonacademic activities. See 34 CFR §300.347(a)(3). If you believe that the exclusion of a student with Asperger's Syndrome from a required field trip would constitute discrimination on the basis of disability in violation of Section 504 or Title II of the ADA, you should contact the OCR enforcement office that serves your State, the name and address of which are provided earlier in this response.

In question 18 of your letter, you request information on options available to the parent if the parent believes that the school district is not offering their child with Asperger's Syndrome an appropriate placement. The Part B regulation at 34 CFR §300.403 concerns children with disabilities enrolled by their parents at private schools when FAPE is at issue. Under that regulation, a public agency is not required to pay for the child's placement at a private school, if the agency made FAPE available and the parents elected to place their child at a private school or facility. However, if a court or hearing officer makes a finding that there has been a denial of FAPE, the court or hearing officer could order tuition reimbursement to the parent for all or part of the cost of the private

school placement. If a parent chooses to home school their disabled child, you would need to consult your State regulations to determine criteria for home schooling and whether any special education and related services would be available to the child.

In question 20 of your letter, you ask whether it is appropriate for either K-12 or postsecondary learning institutions to demand that students with documented language disabilities take/pass foreign language courses even though it represents demanding success in a major area of their disability. With regard to postsecondary institutions, you need to contact the Office for Civil Rights that serves your State to determine whether the requirement to which your inquiry refers violates the Federal civil rights laws. In general, Part B requires that IEPs for students with disabilities focus on their involvement and progress in the general curriculum, that is, the same curriculum as for nondisabled students. 34 CFR §300.347(a)(1)-(2). Therefore, the student's IEP team would need to determine whether the student with a language disability should take a foreign language course and whether any appropriate accommodations or modifications could be provided. The IEP team would also need to consider the applicable State standards. Under IDEA '97, while it is important that students with disabilities be held to high expectations and challenging performance standards, the IEP team would be charged with developing a program for the child that is consistent with the student's goals and disability-specific needs.

Questions 21 through 23 of your letter do not concern Part B, since Part B does not govern requirements of postsecondary institutions. For further information regarding these requirements, you should contact the named official of the OCR office that serves your State at the address provided.

We hope that you find this explanation helpful.

Sincerely,

Kenneth R. Warlick
Director
Office of Special Education
Programs

Enclosure

cc: Shann Goff
Florida Department of Education

Appendix 10

Summary from Dr. Kenneth Friedman on impact of the Physician's Manual for CFS distributed by the State of New Jersey to all of its licensed physicians.

The New Jersey Chronic Fatigue Syndrome Association lobbied the New Jersey State Legislature for an appropriation to produce a Physicians' Manual for the Diagnosis and Treatment of Chronic Fatigue Syndrome. Once that manual had been produced, it was distributed to every licensed physician within the State of New Jersey in an effort to educate physicians practicing within the State of New Jersey about Chronic Fatigue Syndrome. The manual was produced and distributed approximately two years ago and I am pleased to report, albeit anecdotally, that it has improved the recognition and treatment of CFS within the State of New Jersey.

I can report to you that at the most recent meeting of the New Jersey Medical Society, held April 30th and May 1st, 2004, many physicians acknowledged receipt of the Manual and an ability to better recognize and treat CFS. Statements to this effect were made to me as I staffed a CFS Education table (sponsored by the New Jersey Chronic Fatigue Syndrome Association, the Chronic Fatigue Syndrome Association of America, and the Centers for Disease Control) during the meeting.

Other relevant observations from this meeting include: (1) Many physicians expressed interest in the CDC's CFS Continuing Medical Education Course in DVD format (which may be used by the physician at his/her own pace on his/her own computer), and several County Medical Societies in the State of New Jersey expressed preference for a "live" presentation of the CDC, CFS, CME course (which I will be providing).

In my opinion the CFS Diagnosis and Treatment Manual created within the State of New Jersey should serve as a model publication for the United States. The availability of this Manual should not be limited to one state. I would encourage the reproduction of this Manual or one similar to it at the national level.

The Manual has found an equally effective but unanticipated national use: CFS patients from all parts of the United States are contacting me requesting copies of the manual which they can bring to their physicians to educate them on the issues of diagnosis and treatment of CFS. To the extent possible, NJCFSA is filling these requests. Clearly, however, NJCFSA cannot distribute this manual nationwide to all those patients who wish it. NJCFSA does not have the financial resources for a nationwide mailing and there is only a limited number of Manuals in existence.

For all these reasons, I would encourage the CFSAC Subcommittee on Education, as well as the parent CFSAC, to consider making the recommendation that the Manual produced by the State of New Jersey be reproduced by the DHHS and made available to physicians nationwide, or that an equivalent resource be created for physician education and reference.