

June 13, 2002

**NATIONAL HEART, LUNG AND BLOOD INSTITUTE
NATIONAL CENTER ON SLEEP DISORDERS RESEARCH
OFFICE OF PUBLIC EDUCATION & CONTROL
NATIONAL INSTITUTES OF HEALTH**

**PRELIMINARY REPORT: WORKING GROUP ON THE
FEASIBILITY STUDY FOR OUTCOME EVALUATION OF SLEEP
EDUCATION PROGRAMS**

**Natcher Conference Center, NIH
March 20-21, 2002**

EXECUTIVE SUMMARY

Overview

The National Center on Sleep Disorders Research (NCSDR) and the Office of Prevention and Control (OPEC), National Heart, Lung and Blood Institute (NHLBI) organized this Working Group on the Feasibility Study for Outcome Evaluation of Sleep Education Programs to recommend outcome evaluation strategies for one or more of the current sleep education programs. This Working Group is comprised of researchers and clinicians from several different areas ranging from sleep and behavioral research to pediatrics, public health, policy and education.

Purposes and Format

Dr. Carl Hunt, Director of NCSDR, welcomed the group and presented a history of NCSDR programs since the Center was organized in the mid-1990's. NCSDR organizes workshops, initiatives and public education programs and is currently revising its 1996 Sleep Disorders Research Plan. One of the important missions of NCSDR and NHLBI is to disseminate information on sleep and health and through such translation efforts to effect changes in knowledge, attitudes and behavior. Additional information on the Center and its activities can be found on its website: www.nhlbi.nih.gov/sleep.

The charge to this Working Group is to develop evaluation strategies to assess the impact of the current sleep education programs. The Working Group is asked to address the following:

- Assess which of the components of the current educational initiatives are most suitable for a cost-effective outcome assessment;
- Identify which of the target audiences can be studied in a cost-effective manner;
- Find ways to measure baseline knowledge and behavior regarding healthy sleep in target audience(s);
- Suggest methods to measure program impact on knowledge and behavior regarding healthy sleep in targeted audience(s) and sustainability of any observed impact(s).

The mission of OPEC is to coordinate the translation and dissemination of research to the American public, to patients and to health professionals. Members of the OPEC staff presented information on NCSDR Sleep Education Activities, particularly three current sleep education programs: Garfield the Star Sleeper: Sleep Well. Do Well campaign; High School Supplemental Curriculum on Sleep and the Working Group on Sleepiness and Adolescents/Young Adults. Following each presentation, Dr. Thomas Lasater led the Working Group in a discussion of that sleep education program, focusing on types of evaluation strategies most appropriate to each program.

GARFIELD THE STAR SLEEPER: SLEEP WELL. DO WELL CAMPAIGN

Using Garfield, the cartoon cat as the official "Spokescat" for healthy sleep, the Garfield campaign targets 7-11 year olds. Following the press conference starting the campaign in early 2001, an active news media campaign has been developed, including B-roll/soundbite packages, public service announcements, magazine feature articles, back-to-school and daylight savings campaigns. Garfield, the official "Spokescat", has appeared at elementary schools and other locations. Additional materials include a Garfield doll, fun pad, web site, contests, and a toolkit for potential audiences. There are several partners in this campaign and additional partners will be added in the future. There has been no formal evaluation of the Garfield campaign and its success or impact to date.

EVALUATION SUGGESTIONS ON GARFIELD CAMPAIGN

Epidemiological Suggestions

- Who is the Garfield campaign reaching (e.g. children at ? ages, parents, teachers, pediatricians)
- What cognitive and attitudinal changes are being made
- Which superintendents/school principals are adopting the program and which aren't among those reached
- *Note: Could do focus group interviews here or surveys centrally to find out why some are not adopting*
- Website hits: track hits against campaign rollouts in schools to see spikes; get a more detailed breakdown on whom the campaign is reaching and possibly on who is retaining the message

Outcomes Evaluations Suggestions

Need to look at the following:

- Adoption: Do a follow-up visit 6 months after the introduction of Garfield materials to the school to see how much adoption has taken place
- Maintenance of changes, and which ones
- Who the campaign is reaching (this is needed both as epidemiological information and as an outcome)

Note: Answers to the above will give baseline data upon which to build.

- Is the campaign engaging elementary school-age children, and at what grade level(s)?
Note: Some behavioral/attitudinal changes can be inferred as a result of engagement
- Conduct attitude and awareness measures of kids and parents (can also track other gatekeepers such as teachers and pediatricians)
- Do a Pediatric Physicians Survey to show extent of initial awareness of sleep as a priority, then measure how sleep moves up or down the priority list as kids, teachers and parents are exposed to the Garfield program

Process Measures Suggestions

- Media evaluations
- Process evaluations such as partnership formation and ability to sustain partnerships
 - Survey current partners to see what they have and have not gotten from the relationship; add data on what they liked to the toolkit
- Track where engagement is most effective: AARP? PTA? PTO? Schools?

Answers to the above will yield information on extent of exposure and how kids learned about sleep. An NIH demonstration grant to compare educational interventions might be one useful strategy.

- Work with local PTAs to get parental support for programs (parents also then influence pediatricians as well as reinforcing changed attitudes in kids). Give these organizations videos, materials, etc. and consider finding means for them to make some money in the effort as an incentive

Suggestions on Sustainability

- Study with whom to partner
- Need evidence for potential partners that the project is worthwhile
- Assess capacity issues in schools initially, then reassess periodically
- Investigate whether or not some local chapters of national organizations and local colleges might help fund the education effort

General Recommendations

- Modify the toolkit to reach teachers (already in process)
 - * Look at feedback from mail back cards and find out who uses the kit
 - * Track who comes back
 - * Get information on groups, SES data from zip codes in responses

Note: Incorporate elements of OSE programs here in terms of tracking where respondent saw ad, etc.
- Measure user friendliness and efficacy of the materials
- Track costs closely using Best Practices
- Formulate a good marketing plan:
 - * Collect information on the audience
 - * Collect information on what methods are/are not working

- * List steps to be taken by NCSDR and by the partner
 - * Formulate incentives for school principals to adopt this program
 - * Do follow-up 6-12 months post Garfield visit
 - Develop/train "Champions," i.e. local advocates for the program such as Advisory Board member Sandy McGinness.
 - *Note: It was suggested that as part of the training of "champions" effort, an evaluation could be done comparing 3 champions versus OPEC's national efforts to see which approach works better. It was also suggested that physicians who are sleep experts could be utilized in training champions.*
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- When the current R&D contract is renewed, add a clause about a feedback loop in the mass media efforts
 - Target other school systems with central distribution such as Department of Defense Schools, parochial schools, large organizations that have schools associated with them
 - Send mailers to pediatricians when the Garfield campaign is coming to their local schools

HIGH SCHOOL SUPPLEMENTAL CURRICULUM ON SLEEP

The high school supplemental curriculum on sleep was developed in conjunction with the NIH Office of Science Education (OSE). OSE's website is:

<http://science.education.nih.gov>. The Office works with NIH Institutes to produce science curriculum for K-12. The curriculum is designed to meet educational goals of the teachers in major disease areas such as cancer and asthma. The sleep science supplement contains information on sleep, sleep disorders and biological rhythms. It shows the importance of sleep to health and the consequences of inadequate sleep. It is based on the 5E method of teaching: engage, explore, explain, elaborate and evaluate. The sleep supplement is currently completing final review, and is scheduled for general distribution to high schools in Fall 2002.

OSE has already developed an evaluation program of its established high school curriculum supplements. OSE has a grant from the National Science Foundation to study whether schools got the materials, whether the materials were taught and if so, were the teachers impressed with the curriculum, were there problems, etc. They can also track website hits pre and post use of the curriculum although this does not give an exact measure since more than one student can have the same IP address.

EVALUATION PLAN AND RECOMMENDATIONS

Overall Plan

Dr. Bruce Fuchs and Dr. Claire Von Secker agreed to develop an evaluation plan for the sleep supplement curriculum based upon their previous experiences and present it to the

Working Group. The Group will then include that plan to its list of evaluation recommendations and add suggestions for funding the high school curriculum evaluation plan. Some of the questions needed for evaluation are already in the curriculum and some will need to be added. The objective is to show that kids exposed to the curriculum have a greater awareness of sleep issues than those who are not exposed.

Other Suggestions

- Track attitude changes in kids back to the parents who reinforce changed attitudes to see a multiplier effect
- Research other distribution systems for the curriculum such as sleep disorder associations and Foundations.

** The Working Group suggested that Dr. Fuchs look into contacting the Gates Foundation, which has recently given money to fund charter schools in disadvantaged areas to get kids through high school and an associates degree program. Department of Defense schools are another possible partner. OSE needs a controlled environment in which to collect data on users and subsequent achievement, but some associations to defray costs may be possible.*

- Obtain OMB clearance to ask teachers to complete a questionnaire
- Give this sleep curriculum to outreach medical students to go out and teach science
- Society of Behavioral Medicine may be possible user of curriculum

PROGRAM FOR EDUCATING PHYSICIANS

Continuing medical education (CME) for physicians is one objective of the NCSDR Working Group on Sleepiness and Adolescents. The primary target audience is pediatricians and other primary care and subspecialty physicians caring for children. Some sleep disorders may appear even before adolescence but often go undiagnosed and untreated until adulthood, and sleep restriction becomes common in adolescents. Adolescents are undergoing physiological changes at the same time that they are more exposed to risk behaviors including sleep restriction. This group also has the greatest number of car crashes due to sleepiness. Physicians need concise data outlining: signs and symptoms of sleep disorders and problem sleepiness; differential diagnoses; detection protocols; management strategies. The Working Group on Sleepiness and Adolescents has several planned ways of reaching pediatricians to make them more aware of sleep as an issue: 2 publications in a peer reviewed journal (Pediatrics); a CME session at the annual American Academy of Pediatrics (AAP) meeting in Boston in October 2002; assist the AAP in writing a Policy Statement on Adolescents and Sleepiness. Content of the AAP session ("Sleepiness and Adolescents: A Deadly Combination") will include what every pediatrician should know about sleepiness and possible tools to treat it, intervene or refer to another specialist. This session will be videotaped for wider subsequent distribution to primary care physicians for children. The manuscripts to be submitted to Pediatrics will include an algorithm for approaching a sleepy patient, questions to ask, and differential diagnoses.

Recommendations for CME Session-Content and Evaluation

- Have attendees do a pre-post evaluation of one page each
Note: The Working Group was skeptical about how receptive the audience would be to complete an evaluation.
- Content of session:
 - * Perhaps ask the physicians about their own professional/personal experiences with sleep problems/sleep disorders as a means of drawing them into the subject, including why they are there and what they would like to know about sleep problems
 - * Ask attendees to write down their key questions at beginning of session
 - * Do a knowledge assessment of attendees and query them on how they hope to use the new information gained, i.e. what they will incorporate into their practice post session; query them 6-12 months post the session to see if new knowledge has made a difference in their practices
- Dr. David Kaplan will check with AAP about possibly getting a pamphlet on the CME session included in the package of registration materials which is sent to pediatricians
 - * Pamphlet could include pointed clinical questions/answers and an open invitation to possible co-sponsors
- Dr. Kaplan will send a questionnaire to his AAP Section on Adolescence to get baseline data on current knowledge
- Dr. Kaplan will look into getting sleep-related questions (possibly 3) added to the AAP's survey of a sample of its members every two years
- Do follow-up of attendees post the session to start building a network of opinion leaders

Epidemiological Data Needs

- Need a state of the science in sleep
- Need epidemiological data to better define prevalence of sleep restriction and sleep disorders across the range of pediatric ages
- Develop 3 questions on sleep to add to history form completed by patients at initial visit to physician; measure prevalence from those answers
- Contact physicians post initial exposure to sleep issues and survey whether or not sleep is now on their intake questionnaires
- Determine which questions on sleep would be most appropriate to include in CDC surveys

Alliance Partners

- Drivers Education Instructors
- Students Against Destructive Decisions
- Mental health professionals, including pediatric psychiatrists and AAP, and other Federal Agencies
 - * These groups could be partners in looking at impairment, a cross cutting issue which also cuts across age groups
 - Sleep issues may play a role in ADHD
 - Study impact of sleepiness on performance and behavior and mood

- Worksite Wellness of North America (Welcoa-The Wellness Councils of America) who may distribute some of the sleep materials at no cost

Other Recommendations

- Develop Practice Guidelines. These should include:
 - * Treatment options
 - * Social-environmental aspects of sleep
 - * Behavioral interventions
 - * Indications of when to refer, and to whom
 - Develop intake questions related to sleep history, where patient sleeps and time of day, medical conditions present such as snoring or enlarged tonsils
 - Study sleep from a socio-economic perspective
- Obtain epidemiological data that includes the following:
 - * Common misconceptions about sleep in general
 - * Common misconceptions about sleep among physicians
 - * Basic epidemiological data on incidence, prevalence, groups included (from various racial, ethnic, gender, etc. backgrounds), co-risk factors in particular groups
 - * Public health dimensions of sleep
- Dr. Barry Portnoy will contact head of National Center on Health Statistics concerning adding sleep to NHANES
- Appoint someone from the Department of Education to the Sleep Disorders Research Advisory Board
- Put questions regarding sleep on Behavioral Risk Factors Surveillance Study (BRFSS) from CDC. Dr. Portnoy to follow-up here and also work with Dr. Fuchs.
- Healthy People 2020: Add reducing vehicle crashes due to sleepiness as one of the goals. May be able to partner with CDC here.

SUMMARY

The Working Group on Feasibility Study for Outcome Evaluation of Sleep Education Programs has begun to formulate the outline of an evaluation plan. The Working Group will review the report of this first meeting and will meet again either in person or via video conference before finalizing their evaluation plan by late summer 2002. The Group will recommend ways in which NCSDR can determine the impact of its sleep education programs and their influence on knowledge, attitudes and behavior. The Working Group suggested several surveys whose reach may be appropriate to determine more definitive prevalence data on sleep knowledge, behaviors, and problems in the American public in general and in specific at-risk populations. The Working Group also made some suggestions that may prove useful in strategies for marketing and partnering.