## Department of Health and Human Services National Institutes of Health National Institute of Nursing Research Minutes of the National Advisory Council for Nursing Research

May 22-23, 2001

The 44th meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, May 22, 2001, at 1:00 p.m., in Conference Room D, Building 45 (Natcher Building), National Institutes of Health (NIH), Bethesda, Maryland. The meeting was open to the public from 1:00 p.m. until approximately 5:20 p.m. The closed session of the meeting, which included consideration of grant applications, began the next day, Wednesday, May 23, 2001, at 9:30 a.m. and continued until adjournment at 12:00 noon. Dr. Patricia A. Grady, Chair of the NACNR, presided over both sessions except for a portion of the closed session that was chaired by Dr. Mary Leveck, NINR Deputy Director.

## **OPEN SESSION**

## CALL TO ORDER, OPENING REMARKS, AND COUNCIL PROCEDURES

Dr. Grady called the 44th meeting of the NACNR to order, welcoming all Council members, visitors, and staff. She introduced four new Council members: Dr. Jacqueline Dunbar-Jacob, School of Nursing, University of Pittsburgh; Dr. Mary Naylor, School of Nursing, University of Pennsylvania; Dr. Joan Shaver, Dean, School of Nursing, University of Illinois, Chicago; and Dr. David Ward, College of Health Professions, Medical University of South Carolina. The new members' terms will run through January 2005.

## Conflict of Interest and Confidentiality Statement

Dr. Mary Leveck, NACNR Executive Secretary, reminded attendees that the standard rules of conflict of interest applied throughout the Council meeting. She also reminded NACNR members of their status as special Federal employees while serving on the Council and that the law prohibits the use of any funds to pay the salary or expenses of any Federal employee to influence State legislatures or Congress. Specific policies and procedures were reviewed in more detail at the beginning of the closed session and were available in Council notebooks.

## Consideration of Minutes of Previous Meeting

Council members had previously approved the minutes of the January 23–24, 2001, meeting by electronic mail. Dr. Grady thanked the Council members for their timely

feedback on the minutes. The minutes from each NACNR meeting are posted on the National Institute of Nursing Research (NINR) Web Site (<u>www.nih.gov/ninr</u>).

## Dates for Future Council Meetings

Dates for meetings in 2001 through 2003 have been approved and confirmed. Council members should contact either Dr. Grady or Dr. Leveck regarding any conflicts.

## 2001

• September 11–12 (Tuesday-Wednesday) 2002

- January 16–17 (Wednesday-Thursday)
- May 21–22 (Tuesday-Wednesday)
- September 17–18 (Tuesday-Wednesday) 2003
- January 28–29 (Tuesday-Wednesday)
- May 20–21 (Tuesday-Wednesday)
- September 16–17 (Tuesday-Wednesday)

## **II. REPORT OF THE DIRECTOR, NINR**

Dr. Grady announced that this year marks NINR's 15-year anniversary, which will be celebrated in various activities throughout the summer and fall. Further details were discussed during the Council meeting and also may be found on the NINR Web Site and through various announcements to the larger nursing community.

After these introductory remarks, Dr. Grady moved to the director's report, which focused on the following general areas: legislative issues, NIH updates, and NINR updates and outreach activities.

## Legislative Issues

The year 2001 brought in a new administration and many new faces to the 107th Congress. A major activity of Congress in the new year involves proposing a final Federal budget for fiscal year (FY) 2002. Each year, the Congressional appropriations subcommittees hold hearings that focus on how funds will be spent in the upcoming year. As part of these hearings, representatives from various governmental agencies testify before the House and Senate to defend the President's budget. This year, because the President's budget was not available until April 9, the House Appropriations Subcommittee chaired by Representative Ralph Regula, held "theme" hearings during April. Dr. Grady testified with the directors of three other institutes (the National Institute on Aging, the National Institute on Child Health and Human Development, and the National Institute of Environmental Health Sciences) on "lifespan" issues at one of these hearings. The House held its official budget hearings on May 16 and 17. During the House hearing on May 16 and the Senate hearing on May 23, Dr. Grady gave testimony on the NINR, highlighting scientific and public health advances made by NINR-funded researchers in the past year, stories of discovery, and areas of research opportunity for FY 2002 identified by the Council in February 2000. The following findings were among the several studies that Dr. Grady presented to Congress in the NINR testimony.

- *Improved birth outcomes with nurse home visits and telephone counseling.* This study of a population with at-risk pregnancies included low-income African Americans and whites, including pregnant teens. The results showed that the rates of both low-birth weight babies and pre-term births were markedly lower among women receiving home visits by registered nurses (R.N.s) who also provided follow-up telephone counseling compared with those not receiving this intervention (Moore ML. *JNsg Scholarship* 31:349–354, 1999). When data for African Americans were examined separately, the rates improved further. The per-pregnancy hospital savings for the highest risk group was \$277, which does not include the varied costs to families and society that often are associated with low birth weight. This intervention convinced local organizations and a national health maintenance organization to run similar programs, all of which are now operated and funded through the private sector.
- Coping skills training may reduce health risks in youths with diabetes. Much research at the NINR focuses on preventing or managing illnesses that affect the lifespan such as diabetes. Researchers have found that the relatively strict guidelines for controlling blood glucose levels through diet and exercise, as set forth by the Diabetes Complications and Control Trial, are much more difficult to achieve in teens. An intervention that included 6 weeks of specialized training to help youths with diabetes learn to cope with their condition led to a steady improvement in hemoglobin A1c levels for up to 12 months after the training intervention (Grey et al. Journal of Pediatrics 137:107–113, 1999). The coping skills training included role-playing in different social situations in addition to an intensive diabetes therapy program. A1c levels were about 9 percent at baseline for both the control group (which received only the diabetes therapy program) and the intervention group. Levels dropped to about 7.5 percent in the intervention group, but stabilized at about 8.5 percent at 3 months after baseline and remained at that point for the rest of the study for the control group. Sustaining the reduced hemoglobin A1c levels of the intervention group over time could reduce the risk of retinopathy and microvascular complications of diabetes by 30 to 50 percent. The study also showed that the teens in the intervention group became more confident about managing their disease in their daily lives.
- *Transitional care model*. Research funded by the NINR conducted at the University of Pennsylvania showed a significant reduction in the number of days in the hospital, patient readmissions for complications such as infections, and costs when a comprehensive patient discharge plan that included follow-up nursing care by advanced-practice nurses was developed for elderly persons

admitted to hospitals. At 6 months after discharge, the intervention group of older adults with common medical and surgical problems had 65 percent fewer readmission days and 48 percent fewer total readmissions, for a cost savings of 48 percent when compared with controls (Naylor et al. *Journal of the American Medical Association* 281:613–620, 1999).

Dr. Grady also outlined key areas of research opportunity for FY 2002, discussed during the February 2000 Council meeting, under three broad categories:

Chronic illnesses or conditions

- Management of chronic pain, an area of research in which the NINR has had a long-term interest.
- Biobehavioral management and quality of life in persons with cachexia, a research area and condition for which few effective approaches or interventions exist.

Behavioral changes and interventions

• Informal caregiving in non-institutional settings is an area of growing interest as the U.S. population ages and people are living longer with chronic illnesses and want to receive care at home. The NINR will hold a workshop in the summer of 2001 to assess the state of the science and develop possible areas for study.

Responding to compelling public health concerns

- Reduce health disparities in cancer screening.
- Infrastructure development: nursing research training and career development. Nurse shortages exist across the nursing community. This remains a pipeline issue, and the NINR will be addressing training and career development at several levels.

The President's budget designates \$117,696,000 to the NINR, representing an 11.9 percent increase over the FY 2001 NINR budget. This projected increase is below the 13.5 percent projected increase for NIH overall and less than the 28.5 and 16.6 percent increases in the NINR budgets for FY 2000 and FY 2001, respectively. Dr. Grady noted that FY 2001 was a landmark year because NINR's budget passed the milestone of \$100 million for the first time in the Institute's 15-year history. In further discussion of budget issues, Dr. Grady pointed out that certain areas of the overall NIH FY 2002 budget are targeted for increases, such as the new National Center on Minority Health and Health Disparities (NCMHD) and women's health. The final budget signed by President Bush will probably represent a compromise between the President's budget and budget bills developed by the House and the Senate. The House passed the Conference Report for the FY 2002 President's budget on May 9, and the Senate passed the stage for the appropriations bills that emerge from the two chambers of Congress.

### NIH Updates

Several key government and Congressional staff members have visited the NIH since the swearing in of the new administration. Among the visitors was Dr. Tommy Thompson, the recently appointed Secretary of the Department of Health and Human Services (DHHS), which oversees several agencies, including the NIH. Representative Regula, Chair of the House Appropriations Subcommittee, and Representative David Obey, Chair of the overall House Appropriations Committee, also have visited the NIH campus this year. Dr. Grady reported that the visits appeared to leave a favorable impression regarding the NIH.

Another issue of interest at the NIH is the budget-doubling initiative, which projected the NIH annual budget to double between 1999 and 2003. The NIH is preparing for the fourth year of this initiative; it is expected to take at least 1 additional year for the budget to double. Dr. Grady noted that many Congressional members have expressed support for continued increased funding for the NIH. The NINR's immediate and longer range plans for use of any additional funds, and the anticipated impact of those funds, may be found at www.nih.gov/news/BudgetFY2002/investmentplans99-03.htm. National Institutes of Health statements supporting the doubling of the budget may be found at www.nih.gov/news/BudgetFY2002/index.htm.

Another area of focus at the NIH involves the NIH Council of Public Representatives (COPR), established in 1999 by former NIH Director Dr. Harold Varmus to serve as a conduit between the NIH and the public. The COPR includes leaders from across the country who are interested in health issues but who are not involved in scientific or health research *per se*. Some of the issues that the COPR has examined include the protection of human subjects in research, the outcomes of clinical trials in which the investigators have financial stakes in the studies, and measuring the biomedical research needs of various underserved populations. At the May 1 meeting of the COPR, Dr. Grady made a presentation, "Providing Health Through Leadership: A Strategic Plan for Nursing Research," in which she describes NINR's initiatives and programs. Dr. Grady noted that the COPR members expressed interest in the NINR and its research activities.

### NINR Updates and Outreach

As mentioned at the beginning of Dr. Grady's report, the NINR turns 15 this year, and the Institute has several activities planned over the coming months to celebrate this anniversary. Nurse's week at the NIH was kicked off on May 3 with a daylong celebration of nursing research and practice advances that featured several keynote speakers. The week, cosponsored by the NINR and the Clinical Center, also included three segments from the Discovery-Health television series filmed at Johns Hopkins University with comments by nurse researchers Dr. Gayle Page, Dr. Marie Nolan, and Dr. Arthur Engler. The NINR staff plans a new exhibit, campus banners, and posters to highlight the anniversary. The yearlong celebration will culminate in a national symposium on the NIH campus on September 20–21, 2001; the symposium will highlight

scientific advances in nursing research. A gala event sponsored by the Friends of the NINR ("NightinGala") will be held on September 20. Additional information about anniversary events will be posted on the NINR Web Site as soon as it becomes available.

The NINR continues to work with other institutes, centers, and organizations to promote, advance, and integrate nursing research. In one such effort, the NINR is collaborating with the newly established NCMHD on a partnership pilot program to provide supplemental funding to enhance partnerships between majority and minority nursing institutions and organizations with the ultimate goal of building capacity to reduce health disparities among underserved populations. This pilot project takes a multi-tiered approach that seeks to recruit, retain, and train researchers, faculty, and students. Phase 1 awards were extended to seven applications in the pilot partnership program, and the first progress reports are expected within a few months. (See section VII, titled "Report of NINR Conference: Establishing Partnerships To Address Health Disparities and the Career Development of Minority Nurse Researchers" for additional details.)

NINR convened an interdisciplinary meeting of cystic fibrosis (CF) clinicians and researchers on May 1–2, 2001, to discuss symptom management and quality-of-life issues for persons with CF, many who now live well into adulthood. A primary purpose of the meeting was to develop recommendations to strengthen the nursing research opportunities in CF through the NINR CF portfolio, learn from current collaborative research strategies involving foundations, and improve the quality of life of persons with CF and their families. Dr. Margaret Grey served as council representative at that meeting and Dr. Hilary Sigmon provided the NINR leadership. A copy of the executive summary of the meeting will be posted on the NINR Web Site as soon as it is available.

In the area of end-of-life issues, former Council member Dr. Richard Behrman is chairing an Institute of Medicine (IOM) initiative titled "Caring for Dying Children and Their Families," which will examine the little-studied area of issues facing dying children and their families. NINR is a major sponsor of this study. Dr. Grady also reported on a series of six 1-hour videos titled "End-of-Life Care," produced through collaboration between the American Academy of Colleges of Nurses (AACN), the Association of Academic Health Centers, and the NINR. The series will air in multiple locales across the Nation to increase awareness about end-of-life issues and palliative care. Those interested in the video series should contact Dr. Ann Knebel or Mr. Dan O'Neal in the NINR Office of Science Policy and Public Liaison; copies are expected to be available this summer.

In NINR staff news, Dr. Grady announced two appointments at the NINR. Dr. Yvonne Bryan is the new Program Director for Reproductive and Infant Health. Dr. Melinda Tinkle will join the NINR on June 4 as the new Intramural Program Director for Research and Training. Another NINR staff member, Dr. Knebel, is the recipient of the Dr. Faye G. Abdellah Research Publication Award in April 2001.

Dr. Grady also reported on two "nurses in the news." In Tuscaloosa, Alabama, Dr. Mary Starke Harper, a minority nurse with a prolific career as an advocate for geriatric nursing

and geriatric psychiatry, was honored through the hospital dedication of The Mary Starke Harper Geriatric Psychiatry Center. Dr. Harper worked for 30 years for the Department of Veterans' Affairs and an additional 23 years at the National Institute of Mental Health (NIMH). She founded the Minority Fellowship Program and is the former coordinator of Long-Term Care Programs at the NIMH. Also in the news is Dr. Linda Aiken, whose report on nurses' perspectives on hospital care in five countries was published in the May/June issue of *Health Affairs*. Dr. Aiken's report is a critical study that includes important information on the basis for the current nursing shortage and was widely reported in the media.

In a final item, Dr. Grady noted a summary of NINR Web Site usage. It showed that the number of hits (files sent) and visitors to the site has continued to grow over the past 2 years. In March 1999, the site had about 145,000 hits per month; by March 2000, that number had increased to 424,000; and in March 2001, it had grown to 647,000. The number of visitors to the site has been tracked since 2000; data show that in March 2000, some 9,000 visitors logged onto the NINR Web Site, compared with nearly 15,000 visitors to the site just 1 year later in March 2001.

### Questions/Comments

In response to a question about former NIH Director Dr. Varmus's recent article in *Science* about the impact of disease categories on the NIH infrastructure, Dr. Grady commented that Congress did not specifically address this topic during the hearings. However, the legislative language in a directive to the IOM to study the NIH structure to begin after the appointment of a new director did raise this issue. A comment was made that the visibility and support of a disease or discrete area of interest generally are enhanced through a stand-alone institute or center.

## **III. NIH UPDATE: FOGARTY INTERNATIONAL CENTER**

Dr. Gerald Keusch, Director, Fogarty International Center (FIC), and Associate Director for International Research at the NIH, described the history, mission, goals, and research activities of the FIC. He also highlighted key changes made to and concerns about the Helsinki Declaration on Ethical Principles for Medical Research Involving Human Subjects, which was adopted in 2000 by the World Medical Association (WMA).

The FIC has been an integral component of the NIH international research effort since 1968. The FIC mission is to promote and support scientific research and training internationally to reduce global disparities in health. As part of this mission, the Center fosters partnerships between U.S. scientists within and outside the NIH and their counterparts abroad. The FIC supports basic biological, behavioral, and social science research, including research in the fields of economics, demography, and ethics. The FIC's extramural funding supports investigators associated with research institutions, including universities, schools of public health, hospitals, and similar organizations.

The following priorities and rationales support the Center's mission:

- Determining the burden of disease.
- Identifying the relevance of a disease, treatment, or policy to U.S. minority populations.
- Conducting research not possible in the United States (e.g., testing new treatment regimens to inhibit maternal to infant transmission of human immunodeficiency virus [HIV]).
- Promoting humanitarian concerns (e.g., address the importance of equity and social justice and increase capabilities in bioethical reasoning and practice).
- Training U.S. scientists and foreign scientists. For example, its efforts to create a global coalition to address malaria have resulted in the Multilateral Initiative on Malaria, a new type of international collaboration.
- Engaging science diplomacy (e.g., the FIC is involved with a consortium of groups on cancer and related cancer registries in the Middle East; involvement includes understanding various cultures as well as the science).
- Investigating non-communicable diseases (the new agenda) and communicable diseases (the unfinished agenda).
- Supporting local capacity development and infrastructure and partnering with U.S. institutions on a more level playing field with a goal of local autonomy (e.g., identify cohorts of study volunteers and field and laboratory skills to support international trials).

In addition to providing an overview of the FIC, Dr. Keusch also summarized ethical standards and principles discussed and adopted during the 52nd Meeting of the General Assembly of the World Medical Association (WMA) held in Edinburgh, Scotland, in October 2000. The WMA's first set of ethical principles for medical research involving human subjects was adopted at the Association's 18th General Assembly meeting in Helsinki in 1964. Since that time, these principles have been revised and updated several times; the most recent changes were adopted in 2000.

Despite many positive and beneficial changes, the Helsinki 2000 principles raise several concerns:

- Are principles adequately grounded in the reality of developing international research? Do the principles allow for proper consultation?
- What authority can the WMA claim, and does its authority supersede national laws?
- Can the WMA's guidance be reconciled with U.S. policy and are the Helsinki guidelines relevant to the United States?

The Helsinki 2000 WMA Declaration can be found by linking to "The Declaration of Helsinki" at <u>www.wma.net</u>.

### Questions/Comments

Regarding a question about the leadership and philosophy underlying WMA's principles and guidance, Dr. Keusch stated that the WMA views medical research and education primarily from a Western European perspective. The Association overall does not have strong representation from developing countries, thus producing a disconnect between medical research from a "Westernized" perspective and the range of realities facing most less-well-developed countries.

Another meeting attendee inquired about the obligation of the NIH or FIC to continue to provide HIV/AIDS drugs to infected persons in developing countries once NIH-funded trials in those regions of the world have concluded. Dr. Keusch commented that the NIH and FIC feel a moral obligation to continue providing effective medications to study participants. However, the NIH's role is to conduct research, and it is not mandated to set up follow-up programs. The NIH can entreat other agencies, such as the Agency for International Development, to carry out that mission. Dr. Keusch noted that there is an increased international call to decrease drug prices and to increase distribution and access among developing nations facing the AIDS epidemic. Experts estimate that it will cost \$11 to \$12 billion to set up the infrastructure to accomplish this goal, however. The United States, as one of only a handful of nations that have offered support, has coordinated global response. Even smaller countries can take steps to help their people, however, as evidenced by the strong leadership of Uganda; further advances may be made when countries join together in partnerships.

## **IV. THE NURSING SHORTAGE IS EVERYONE'S BUSINESS**

As Dr. Grady noted in her presentation, there is heightened interest in the growing shortage of nurses in America and around the world, both within and outside of the nursing community. One estimate projects a 20 percent shortfall in the nursing supply in the United States by the year 2020. Faced with such estimates and other testimony, the public, legislators, and the media are beginning to recognize the importance and potential impact of the nursing shortage on the country.

Dr. Carolyn Williams, President, American Association of Colleges of Nursing (AACN), and Dean, University of Kentucky College of Nursing, provided AACN's perspective on the current and projected nursing shortage, offered a snapshot of student enrollment and faculty recruitment and retention issues, identified possible determinants of the shortage beyond enrollment, and described initiatives to help remedy the problem, with a focus on faculty recruitment.

Several factors are contributing concomitantly to the current nursing shortage. Longitudinal data from the National League for Nursing show that the number and proportion of students enrolling in basic nursing education programs (associate, baccalaureate, and diploma programs) have shifted between 1981 and 1996. Most recent data from 342 schools indicate a decline in enrollment in baccalaureate degree nursing programs over the past 6 years, with an average decrease of approximately 3,000 students per year. The AACN anticipates that these trends will continue as the impact of the overall declines in enrollments is seen in coming years.

Enrollment in masters degree nursing programs between 1996 and 2000 at 269 schools shows a similar trend of declining enrollments, with an average of 337 fewer students entering such programs each year. A considerably higher proportion of M.S. nursing students are in part-time rather than full-time programs; the number of full-time students is on the rise, while the number of students in part-time programs is dropping. In contrast with data for basic, undergraduate, and masters level programs, the number of students enrolling in doctoral nursing programs at 73 schools has remained relatively constant in the past 5 years. To stem the current and anticipated faculty shortages, however, enrollment in Ph.D. and other doctoral programs needs to increase sharply. Dr. Williams commented that many of AACN's efforts, including legislative activities, involve securing funds to attract students to full-time study.

Data from a March 2000 national survey conducted by the Health Resources and Services Administration (HRSA) revealed that among R.N.s prepared for advanced practice, the largest proportion (45 percent) are nurse practitioners (N.P.). Fewer than 28 percent are clinical nurse specialists (C.N.S.). Approximately 15 percent are nurse anesthetists, 7.5 percent are N.P.s/C.N.S.s, and about 5 percent are nurse midwives. Dr. Williams pointed out that, with the exception of nurse anesthetists, most of these nurses do not work in hospitals. She noted further that Dr. Aiken's recent study, combined with these HRSA data, indicate that nurses with advanced training and experience are leaving the hospital to pursue careers in other settings and roles that provide more autonomy and a greater opportunity to be a practitioner.

The nursing shortage extends beyond declines in student enrollments and shifts in programs of study at educational institutions. Difficulties associated with the recruitment, retention, and retirement of nursing faculty play a role in the projected nursing shortfalls. The AACN survey also inquired about faculty vacancies at SONs, where faculty positions were defined as being full-time funded positions. Vacancies were about 8 percent across the board.

The National Sample Survey shows that the R.N. population is aging. In 1980, most nurses were in the 20s; in 2000, the age distribution has shifted so that the largest proportion of nurses are in their 40s. With the across-the-board declines in enrollment in B.S.N. and M.S. nursing programs in the past 5 years, and no change in enrollment in doctoral nursing programs, increases in the average ages of nursing faculty is far from encouraging. Regarding the increased average age of the nursing field, Dr. Williams pointed out that 50 percent of nursing students receiving a doctoral degree are in the 45-to 55-year age group. In contrast, the average age among doctorate recipients in *all* fields of graduate study in 1999 was 33.8 years. Part of this "pipeline" problem is the amount of time between earning one degree and progressing to the next educational level. On

average, nurses work for 5 to 10 years after earning a B.S.N. before entering a masters degree program; a similar amount of time passes after receiving an M.S. and entering a Ph.D. degree program.

In an effort to identify why enrollment in nursing programs has been decreasing and to find strategies to correct this problem, the AACN held a series of forums in 1999 that explored this issue. These forums revealed that:

- Potential nursing students are confused by the reality that graduates of diploma, A.D., and B.S.N. programs take the same licensure exam and have very similar entry-level practice opportunities.
- School counselors do not value nursing as an intellectual enterprise.
- School counselors steer brighter students into other majors such as medicine, business, and law.
- Strains in the health care environment, including the decline in the infrastructure to support nursing staff, have contributed to problems with retention and recruitment efforts.
- Extensive R.N. layoffs have had unintended consequences.
- Major shifts in the career aspirations of women, including the perception that nursing is not as attractive as other career options, have influenced the overall changes seen in the nursing field.

In 1994, Friss reported on the ebb and flow of nursing shortages in the 20th century and how imminent or anticipated shortages have been and can be addressed (Friss L. *Policy and Law*, 3:597–631, 1994). Historically, the usual first line of defense in countering a shortage has been to run positive image campaigns and to boost recruitment efforts. However, he suggested taking a different tack that involves focusing on the core issues of:

- Employment practices that hinder nurses' autonomy.
- Narrow salary ranges.
- Minimal extra pay for working undesirable shifts.
- The lack of association between education, training, and pay.
- The lack of connection between education and job level.

In applying this approach to the current situation, the AACN found that at university health systems, although chief nurse officers perceive clear differences in practice between B.S.N.-prepared nurses and A.D./diploma-trained nurses, there is little differentiation in salary and role descriptions between these two groups.

The AACN has begun to address the issue of the decline of nursing by concentrating on increasing the viability of nursing as a professional career option for talented young women and men. The College's efforts will focus on:

- The need to improve the practice environment.
- The transition of new graduates into practice roles.
- The need to differentiate roles.
- The linkage between education and licensure.

- The need for earlier progression into advanced practice roles, research, and education.
- The need to develop definable career pathways that attract talent.
- The linkage between compensation, education, and professional role.

Dr. Williams reported that the AACN also is very concerned about and interested in building the faculty of the future. It has identified several key short-term, targeted approaches to implement immediately:

- Identify untapped populations of potential students.
- Develop strategies for the transition of new graduates into professional practice.
- Increase the collaboration between faculty and nurse clinicians in practice settings, particularly in expanding enrollments.
- Seek federal support to ease student selection of nursing as a major.

The AACN's initiatives to achieve these goals include collaborating with university health system consortiums to develop a model post-B.S.N. residency and to develop strategies to boost enrollment in B.S.N. degree programs.

The AACN has two new initiatives, including a task force on hallmarks of professional practice environments and a task force on education and regulation that considers new models for professional education. In closing her presentation, Dr. Williams asked whether it is time to develop a new model for preparing professional nurses. She quoted from Carole Anderson's column in the November/October 2000 issue of *Nursing Outlook*:

We have to wake up to the fact that nursing does not and will not attract sufficient numbers of bright capable people to the profession as long as it remains at the bottom of the educational level and, *de facto*, reputational ladder. Nursing has lost bright women who are interested in a health profession to other disciplines such as medicine, pharmacy, dentistry, and allied health—all graduate professional degree programs. As this has been happening, the nursing profession has waged an aggressive, internal battle to retain the right to be the least educated of all the health professions—and the battle has been won.

### Questions/Comments

Attendees agreed that changes at all levels, including changing the perception and realities of nursing as a career, are needed. Attendees also supported the idea of nurse internship programs to better prepare students for work in various practice environments, including hospitals. One council member noted that attention is needed to define the nature of relationships between doctors and nurses; Dr. Williams indicated that the AACN would likely be interested in examining this issue with the American Organization of Nurse Executives. NINR will continue to find ways to address the nursing shortage issue, including activities such as increasing early entry into research careers and improving the scientific knowledge base for nursing practice.

### V. NINR RESEARCH ACTIVITIES: "SLEEP RESEARCH"

Dr. Karin Helmers, Program Director, NINR, highlighted activities and findings of NINR-supported investigations in the Institute's portfolio on sleep research. The portfolio includes studies of the impact of sleep deprivation across the lifespan in healthy populations; sleep disturbances in patients with chronic illness, and management of sleep disturbances. The NINR currently is receiving grant proposals in response to a program announcement (PA 00-046) on "Biobehavioral Research for Effective Sleep" that was published in 2000.

One NINR-funded project investigating sleep across the lifespan included a meta-analysis of 1,295 research reports to identify overall sleep patterns in association with age and gender. The analysis found that as one ages, the amount of time needed to fall asleep increases, as do sleep fragmentation and early morning awakenings. Women self-report greater age-related sleep decline, whereas men show a greater objective decline in sleep, as measured by polysomnography. Finally, the meta-analysis indicated that a significant component of age-related changes in sleep are due to health status of the individual. Additional studies of sleep across the lifespan report that women with poor sleep have higher distress, musculoskeletal pain, and fatigue. Research also indicates that for middle-aged and older women, disturbed sleep is related to menopausal symptoms but not menopausal status. Data from other studies demonstrate that first-time mothers do not return to pre-pregnancy sleep patterns. Ongoing experimental studies in the NINR portfolio are examining the consequences of sleep deprivation in adults, behavioral and emotional responses to sleep deprivation in children, and immunological changes in sleep-deprived animals. One successful campaign launched by the National Heart, Lung, and Blood Institute and the National Center for Sleep Disorders Research helps children understand the importance of sleep with the aid of the cartoon character Garfield. A Web Site promoting Garfield's "Star Sleepers" includes games and contests, a "fun pad" for kids, and facts about children and sleep.

The NINR also has supported investigations of sleep disturbances in association with chronic illnesses. One series of studies has examined sleep patterns in persons with fibromyalgia (FM), a condition that affects primarily women in their 40s through 60s and that is characterized by extreme fatigue, restless sleep, pain, and stress. In these studies, women with FM had low sleep efficiency and fragmented sleep. These researchers have found a relationship between sleep latency; sleep efficiency and prolactin confirming their belief that there is some type of neuroendocrine dysregulation occurring in fibromyalgia. Further, in an experimental paradigm, the sleep in healthy women was disrupted and resulted in a reduced pain threshold, and increased discomfort and fatigue, changes that are similar to the symptoms of fibromyalgia. This suggests that sleep is an important factor in fibromyalgia. Studies of hemodialysis patients indicate that the hemodialysis procedure increases core body temperature for 2 hours postdialysis and those patients undergoing hemodialysis experience increased sleepiness during the day and sleep disruption at night. Ongoing studies in this portfolio are examining sleep disturbances in

patients with cancer, obstructive sleep apnea, irritable bowel syndrome, Alzheimer's disease, and coronary artery disease.

Dr. Helmers described some preliminary findings of ongoing NINR-funded studies on sleep disorders. In one study, researchers are developing profiles of stimulant responders and non-responders among persons with narcolepsy. Data suggest that about one-third of persons with narcolepsy did not respond favorably to available treatments; nurse researchers are cataloging factors that appear to influence which patients respond to treatment and which patients do not. Another study is assessing objective physiological parameters (e.g., pupil size) associated with daytime sleepiness to improve upon or replace current measures.

Studies on the management of sleep disturbances will help identify interventions to ameliorate or eliminate the problems causing or associated with the disturbance. Research projects in this area of the NINR portfolio include investigations of insomnia in community-dwelling elders (e.g., in nursing homes); sleep-related morbidity parents of newborns; and the role of skin-to-skin contact in sleep among premature infants. Researchers funded by the NINR also are studying the effectiveness of a nighttime alarm system to monitor wandering in Alzheimer's disease patients and the implementation of individualized daytime activities as an intervention to replace daytime napping and improve sleep at night. Other ongoing studies are examining the role of melatonin in patients with Parkinson's disease and the impact of melatonin plus behavioral interventions on people with jet lag and shift workers. In addition, light therapy is being studied as a potential intervention in managing sleep disturbances in Alzheimer's disease patients.

The NINR has committed resources to the training of sleep researchers through institutional training grants, career development awards, and individual National Research Service Awards (F31s). K01s have been awarded to investigate sleep patterns in patients who have had a coronary bypass and in persons with HIV/AIDS. These training opportunities will prepare nurse researchers to conduct sleep research.

Future endeavors will focus on the consequences of acute and chronic sleep deprivation, particularly in vulnerable populations such as shift workers and premature infants; the effects of restorative sleep; the development of innovative, practical interventions to mitigate sleep disturbances and their symptoms; the identification of effective clinical and behavioral interventions; and the phases and impact of recovery from sleep deprivation. The NINR also will continue its support of training of nurse scientists in the field of sleep research.

## VI. SCIENTIFIC PRESENTATION: "CHRONICALLY REDUCED SLEEP: DO WE COPE, ADAPT, OR DETERIORATE?"

Dr. David Dinges, Professor of Psychiatry; Chief, Division of Sleep and Chronobiology; and Director, Unit for Experimental Psychiatry, at the University of Pennsylvania School

of Medicine, summarized findings of NINR-supported research focusing on chronic sleep loss and the "sleep debt" resulting from the lack of sleep over time. The field of sleep research is exploding, and there are several reasons for this increased interest in sleep and sleep disturbances. Of importance are data suggesting that Americans of all ages, including children, are sleeping less and experiencing more problems associated with insufficient sleep. The impact and burden of this growing lack of sleep on individuals and society are not fully known, however.

Sleep, like eating, is fundamental to quality of life. Chronic sleep reduction frequently is experienced as a result of medical conditions such as pain; neuropsychiatric disorders such as depression; and sleep disorders such as insomnia. A chronic lack of sufficient sleep also occurs in millions of people because of socially induced disturbances in sleep that result from overtime work, being on-call, caring for dependents, shift work and jet lag. Sleep debt resulting from early school start times and developmental factors appear to be common in adolescents and young adults, where it may have a negative impact on the ability to learn and perform in school. Sleep debt also is a primary contributor to the high rate of fatal motor vehicle crashes, especially among younger persons.

A survey (n = 1,004) conducted this year by the National Sleep Foundation found that most Americans get an average of 7 hours of sleep on weeknights and 7.8 hours on weekend nights. However, approximately 31% of Americans get 6 hours or less sleep per night. In addition, 53 percent of Americans report having driven while drowsy, and 19 percent have dozed off while at the wheel.

Dr. Dinges noted that earlier sleep research studies, conducted between 1935 and 1995, were hampered by a number of methodological limitations. Technological and methodological breakthroughs since the mid-1990s-such as greater understanding of sleep and recovery and of brain structure and function, and improved measures of brain wave activity under conditions of sleep deprivation—have advanced the field significantly. The more recent view of sleep disturbances as medical problems also is influencing the field. Dr. Dinges noted that since WWII, the amount of sleep humans need to function effectively has become increasingly controversial. This controversy is influenced by: 1) the finding that sleep disturbances from medical conditions are pervasive; 2) the development of prolonged nocturnal and/or irregular work hours as modern societies with artificial light and cheap energy have exploited time; and 3) the impact of changes in lifestyle coupled with technology on the growing number of work, school, family, and social activities and opportunities that fall outside natural day and night cycles. The controversy has centered on the duration of sleep needed to maintain an optimal—or even adequate—waking neurobehavioral, cognitive, physical, and emotional functions.

Most of the sleep research conducted at the University of Pennsylvania has focused on this controversy: 1) determining the minimum amount of sleep needed for stable waking functions (e.g., physiological alertness/sleepiness, attention and cognitive performance, fatigue, mood, neuroendocrine profiles, neuroimmune responses, health); 2) assessing the temporal dynamics of changes in these functions when sleep is chronically restricted in a dose-dependent manner in a highly controlled environment; and 3) testing the effectiveness of countermeasures to these changes. Dr. Dinges noted that NINR funding has supported key scientific experiments of these questions. Three theories on the amount of sleep required by humans have been tested in these experiments and are listed below:

The core hypothesis assumes that only a "core" amount of sleep (i.e., 4 to 6 hours per day) is needed to maintain effective cognitive and neurobehavioral function. Thus, as long as this core sleep need is satisfied, humans can cope with reduced sleep via reduced sleep need and/or intensified sleep physiology. No cumulative impairment in any function occurs as long as sleep duration is at the core level or higher. The adaptation hypothesis states that chronic sleep restriction is initially disruptive of waking functions, but eventually adaptation occurs with a resulting return of effective cognitive and neurobehavioral functions in the presence of reduced sleep time. The sleep debt hypothesis suggests that the basic adult human sleep need averages approximately 8 hours per day and that any reduction in this duration will contribute to an accumulation in waking cognitive and neurobehavioral deficits. The accumulation also will reflect sleep dosage, such that greater sleep restrictions will yield more rapid accumulation of deficits. This hypothesis posits that there is little or no coping or adaptation when sleep is chronically restricted.

To test these hypotheses, Dr. Dinges and his colleagues conducted three large experiments involving a total of 180 healthy adults who were sequestered 24 hours a day for 14 to 20 consecutive days and randomized to receive 4 to 8 hours of nighttime sleep. Cognitive, physiological, and behavioral variables of each participant were monitored daily. The researchers controlled for the methodological problems and limitations of earlier studies cited above. Statistical modeling showed near-linear accumulations in daytime cognitive performance impairment that were dose dependent across days of sleep restriction. These findings were consistent with the sleep debt hypothesis. In contrast, estimates of self-reported sleepiness, fatigue, and tiredness tended to show adaptation responses, which resulted in modest levels of fatigue at times of greatest neurobehavioral impairment. Vigilance impairment, wake-state instability, and cognitive impairment after chronic restriction of 4 to 6 hours of sleep per day rapidly reached levels that were equivalent to having had one night without sleep; over 2 weeks of sleep restriction, impairment in these functions declined to levels equivalent to having gone two consecutive nights without sleep, even among participants who had 6 hours of sleep each night. Thus, limited sleep led to cumulative functional deficits. However, adequate recovery sleep reversed these deficits.

Establishing that chronic nocturnal sleep restriction produces cumulative neurocognitive impairments and waking physiological changes has expanded the scope of issues to be addressed. Current experiments seek to establish the consequences of chronic sleep restriction at different circadian phases; that is, the amount of sleep is restricted, and participants sleep at different times of the day to mirror a rotating shift-work, such as the kind experienced by many nurses. The hypotheses currently being tested in these

experiments and related studies in Dr. Dinges' laboratory involve: 1) describing changes in physiological markers of homeostatic sleep drive relative to waking alertness function; 2) statistical modeling of the amount of sleep "needed" and its circadian placement to prevent the development of cumulative neurobehavioral deficits; and 3) identifying the effects of behavioral (e.g., naps, timing and duration of recovery sleep) and pharmacological (e.g., caffeine) countermeasures on dose-response functions. Future studies also should seek to investigate the role of sleep debt in morbidity and mortality in special populations with high risk of exposure and clarify the metabolic, hormonal, and immunological effects of chronic sleep loss.

### Questions/Comments

Attendees inquired about Dr. Dinges' report on the results of National Aeronautics and Space Administration (NASA) studies of sleep patterns of astronauts in space, who consistently seem to sleep for only 6 hours daily and yet function effectively. Dr. Dinges stated that the reason for this apparent chronic "sleep deficit" is not clear. Another interesting finding from NASA studies indicates that sleep apnea disappears in space, suggesting that this condition is related to gravity. Regarding an individual's ability to adapt effectively to chronic sleep reductions (i.e., less than 8 hours per day), Dr. Dinges noted that it is likely that few persons truly can function effectively under these conditions and that this ability, when it exists, is probably tied to genetic factors.

## VII. REPORT OF NINR CONFERENCE: ESTABLISHING PARTNERSHIPS TO ADDRESS HEALTH DISPARITIES AND THE CAREER DEVELOPMENT OF MINORITY NURSE RESEARCHERS

Council member Dr. Dorothy Powell and Dr. Carole Hudgings, Chief, NINR Office of Extramural Programs, reported on a new joint initiative between NINR and the National Center on Minority Health and Health Disparities (NCMHD) to build capacity for nursing research on health disparities. This new initiative, which will be piloted in NINR's extramural research program, was presented at the February 5-6, 2001, meeting, "Establishing Partnerships to Address Health Disparities and the Career Development of Minority Nurse Researchers." A summary of the meeting can be found at www.nih.gov/ninr/news-info/meetings.html.

The mission of the meeting was to create partnerships to address health disparities research and assist in developing the careers of minority nurses. A total of 40 participants- representing 7 majority and 9 minority institutions/organizations-attended the meeting as well as a number of other NIH staff. Institutions/organizations represented included the University of Iowa; Alcorn State University; Yale University; Howard University; the University of Pennsylvania; Hampton University; the National Coalition of Ethnic Minority Nurses Associations; the University of Texas, Austin; New Mexico State University; the University of New Mexico; the University of Michigan, Ann Arbor; the University of Texas Health Science Center at San Antonio; the University of

California, San Francisco; the University of Puerto Rico; the University of North Carolina, Chapel Hill; North Carolina Central University.

The following criteria were used by a planning committee comprised of staff from the NINR and the NCMHD as well as outside consultants to select conference participants:

- Majority institutions
  - Willingness to partner with a minority institution(s)
  - Prior partnership experience
  - Minority representation within the institution
  - Willingness to assist in the training and mentoring of minority nursing students and faculty as researchers
  - Commitment to improve the health of minorities and medically underserved populations
  - Recipient of a P30 or R01 grant from the NINR
  - Diverse geographic distribution (as a group).
- Minority institutions
  - Willingness to build upon existing institutional strengths
  - Willingness to assist in building the research capacity at the institution and within the field of nursing
  - Institutional commitment to support and collaborate with others to develop faculty and students, and participate in research.

The aims of the new pilot initiative are to:

- Expand the cadre of nurse researchers involved in minority health research, with a focus on increasing the number of minority nurse researchers in the field.
- Train non-minorities to participate in and carry out research in underserved communities.
- Increase the capacity for health disparities research by expanding the number of SONs involved in such research at minority institutions and institutions located in geographical regions that experience a disproportionate burden of illness.
- Provide a viable career foundation for nurse researchers in the area of health disparities.

The goals of the meeting and the initiative are in concert with the *Healthy* People 2010 goals to eliminate health disparities.

Support for the planning and development of the partnership pilot project was offered through administrative supplements to existing NINR core centers (P30s) or research projects R01s), with funding from NCMHD and NINR. This mechanism allowed consortium and subcontracts to partnering schools. The four broad research areas that

were targeted under this pilot project were: (1) health disparity and disease prevention research, (2) research training, (3) health disparity research education, and (4) research outreach.

Standard peer-review criteria (significance, approach, innovation, investigator, environment) plus the following criteria were used in reviewing the applications:

- Evidence of linkage between the proposed initiative and the currently funded R01 research study or the core center
- Evidence of a proposed or existing partnership between the institutions/ organizations and a strong commitment to develop and sustain a partnership that is mutually beneficial
- Plans for follow-up and evaluation of the effectiveness of the proposed initiative
- If the initiative is related to research training, evidence of qualified faculty and resources at the major institution and a sufficient participant pool at the minority institution
- If the initiative proposes a pilot project, evidence that the conceptual framework, design, methods, and analyses are adequately developed and appropriate.

The awards were made to institutions in a variety of geographic locations and represent a diverse range of topics. Progress reports are due in approximately 3 months; the second wave of funding will occur after review of these reports.

## Questions/Comments

In response to a question about the distribution of work between the partnering institutions, it was noted that the workloads are mixed, fluid, and based on the differing needs and capabilities at the different sites. The work models are dynamic, with many activities taking place at the minority institutions. Future assessments of the initiative will include examining the feasibility of maintaining long-distance partnerships, such as that between the University of California, San Francisco, and the University of Puerto Rico.

## **CLOSED SESSION**

This portion of the meeting was closed to the public in accordance with the determination that this session was concerned with matters exempt from mandatory disclosure under Sections 552b(c)(4) and 552b(c)(6), Title 5, US Code, and Section 10(d) of the Federal Advisory Committee Act, as amended (5, USC Appendix 2).

Members absented themselves from the meeting during discussion of and voting on applications from their own institutions or other applications in which there was a potential conflict of interest, real or apparent. Members were asked to sign a statement to this effect.

## **VIII. REVIEW OF APPLICATIONS**

The members of the NACNR considered 148 research and training grant applications requesting \$117,737,395 in total costs. The Council recommended 102 applications with a total cost of \$85,213,745.

## IX. OTHER ITEMS FOR CLOSED SESSION: EXECUTIVE SESSION

There were no items for discussion. An executive session was not held.

### X. ADJOURNMENT

The 44th meeting of the NACNR was adjourned at noon on May 23, 2001.

### **CERTIFICATION**

I hereby certify that the foregoing minutes are accurate and complete.

Patricia A. Grady, Ph.D., R.N., F.A.A.N. Chair National Advisory Council for Nursing Research Mary D. Leveck, Ph.D., R.N. Executive Secretary National Advisory Council for Nursing Research

### **COUNCIL MEMBERS PRESENT**

Dr. Patricia A. Grady, Chair Dr. Mary Leveck, Executive Secretary, NINR Mr. Gene Blumenreich Dr. Kathleen C. Buckwalter Dr. Margarethe Cammermeyer Dr. Jacqueline Dunbar-Jacob Dr. Margaret Grey Dr. David Hanley Dr. Roseanne Harrigan Dr. Mary Naylor Dr. Dorothy Powell Dr. Joan Shaver Dr. David Ward Dr. Betty Smith Williams Dr. Paulette Cournoyer, *Ex Officio* 

### MEMBERS OF THE PUBLIC PRESENT

Dr. Jean Anthony, Howard University Hospital
Ms. Debbie Campbell, American Association of Colleges of Nursing
Ms. Mary Cerny, The Scientific Consulting Group, Inc.
Ms. Jeanne Epps, Howard University Hospital
Ms. Rita Jablonski, University of Virginia
Ms. Barbara Moran, University of Virginia
Ms. Terri Nally, National League for Nursing
Dr. Barbara Parker, University of Virginia
Dr. Cornelia Porter, University of Michigan
Ms. Cynthia Renn, University of Maryland at Baltimore

#### FEDERAL EMPLOYEES PRESENT

Dr. Nell Armstrong, NINR/NIH Dr. Yvonne Bryan, NINR/NIH Ms. Linda Cook, NINR/NIH Ms. Janet Craigie, NHLBI/NIH Dr. Susan Dorsey, NCI/NIH Ms. Marianne Duffy, NINR/NIH Dr. Roland Garcia, ODEO/NIH Ms. Kay Johnson-Graham, NINR/NIH Ms. Shelma Grant, NIDCD/NINR/NIH Ms. Robin Gruber, NINR/NIH Dr. Karin Helmers, NINR/NIH Dr. Carole Hudgings, NINR/NIH Dr. David Introcaso, NINR/NIH Dr. Ann Knebel, NINR/NIH Ms. Cindy McDermott, NINR/NIH Dr. Gertrude McFarland, CSR/NIH Dr. Pedro Morales, OEO/NIH Ms. Tara Mowery, NINR/NIH Mr. Daniel O'Neal, NINR/NIH Dr. Janice Phillips, NINR/NIH Ms. Teneka Pierce, NINR/NIH Mr. Heriberto Rivera, NINR/NIH Mr. William Rosano, NINR/NIH Ms. Arlene Simmons, NINR/NIH Mr. Robert Tarwater, NINR/NIH Mr. Mark Waldo, NINR/NIH Ms. Kimberly Witherspoon, NINR/NIH Ms. Sally York, NINR/NIH

#### **ROSTER: NATIONAL ADVISORY COUNCIL FOR NURSING RESEARCH**

(Terms expire on January 31 of the indicated year)

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