DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

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Justification

National Institute of Nursing Research

Authorizing Legislation: Section 301 of the Public Health Service Act, as amended. Reauthorizing legislation will be submitted.

Budget Authority:

FY 2000 Actual		FY 2001 Estimate		FY 2002 Estimate		Increase or Decrease	
FTEs	BA	<u>FTEs</u>	BA	FTEs	BA	FTEs	BA
42	\$90,261,000	50 \$105,1	78,000	59 \$11	7,686,000	9	\$12,508,000

INTRODUCTION

This document provides justification for the Fiscal Year 2002 activities of the National Institute of Nursing Research (NINR), including HIV/AIDS activities. A more detailed description of NIH-wide Fiscal Year 2002 HIV/AIDS activities can be found in the NIH section entitled "Office of AIDS Research (OAR)."

The National Institute of Nursing Research supports clinical and basic research that provides the scientific basis for the care of individuals across the life span. This body of research has a broad scope--from managing the care of patients during illness and recovery, to providing palliative care for individuals at the end of life when recovery is no longer possible. The research NINR supports may also be employed to promote healthy lifestyles and reduce the risk for disease and disability. The goals of the Institute's research are to ease the symptoms of acute and chronic illness, to prevent or delay the onset of disease or disability or slow its progression, to find effective approaches to achieving and sustaining good health, and to improve the clinical settings in which care is provided. All of these efforts focus on the provision of patient-centered, cost-effective care that leads to a better quality of life for individuals, their families or caregivers, and the communities in which they live.

<u>Overview</u>: The activities reported below demonstrate the Institute's progress in contributing research knowledge for the Nation's health. The story of discovery provides the results from many years of work by a nurse-led team to reduce low birth weight and preterm infants in low income, high risk women who are primarily African American adolescents. The team partnered with both public and private sectors of the community to implement research findings into a self-sufficient, economically viable model that does not require Federal dollars to sustain it. The research has resulted in a highly successful model of care which improves the clinical outcomes and quality of life of patients and families. The science advances selected for this year represent

important contributions in four critical areas of science and health care: the feasibility of conducting randomized clinical trials for cancer risk reduction in women with a genetic predisposition for breast and ovarian cancer; interventions to improve the ability of cognitively impaired nursing home residents to perform bathing and dressing activities; factors contributing to stress among family members who made decisions to withdraw life sustaining technologies; and effects of physical activity and inactivity on the cardiovascular risk factor of obesity in adolescents.

Research initiatives to be undertaken in FY 2002 target several national health concerns. They include developing interventions to help an estimated 50 million patients in the U.S. better manage chronic pain; testing interventions to and manage cachexia, a syndrome characterized by muscle wasting, weight loss, and fatigue; assisting caregivers of chronically ill patients with skills and knowledge needed for home care; expanding health promotion research related to cancer prevention in minority populations; and providing training opportunities to meet a specific recommendation from the recent report by the National Research Council of the National Academy of Sciences. This report addresses future needs for biomedical and behavioral research scientists. The 2002 research initiatives will build on a base of ongoing studies in the NINR's research portfolio or extend currently tested mechanisms which support research training. Because many of the NINR's research interests relate to those of the other NIH institutes and centers as well as other public health agencies, collaboration is integral to all of the research initiatives.

These 2002 research initiatives are complemented by activities designed to increase [resources and] numbers of well-prepared scientists for nursing research. Because individuals who enter nursing research often have advanced clinical experience, NINR is intensifying its efforts to provide diverse training and career development programs that meet the needs of individuals along a continuum of academic and clinical backgrounds. A second Summer Genetics Institute is planned for June and July 2001 to capitalize on a very successful first offering in the Summer of 2000. The Summer Genetics Institute provides nurses with knowledge and skills in genetics and genetic research for clinical practice, research, and education.

The Institute continues to have a close working relationship with scientists and clinicians in many disciplines, as well as with those in nursing practice, administration and education. During the past year we have also sought input into the direction of our research from the community at large. Strategic plans developed with community input included a five year overall plan and a specific strategic plan to reduce health disparities. Two events were designed to facilitate dialogue with the public to advise our research agenda in end of life care. These events capitalized on NINR's role as the lead Institute at NIH in end-of-life research and issues.

Substantial growth is reflected in the science achieved by the NINR in just less than fifteen years. The research initiatives described below will ensure this momentum into the 21st century.

Story of Discovery Reducing Low Birth Weight and Preterm Births: Moving Research into the Community

Seven babies per 1,000 born in the United States will die before their first birthdays, an infant mortality rate that places the U.S. a disappointing 25th among industrialized nations.¹ Studies associate these deaths with low birth weight (less than 5.5 lbs.) and prematurity (less than 37 weeks' gestation), and their prevention has become a public health goal.

Low birth weight and preterm births occur with greatest frequency among adolescents and African American women. The national low birth weight rate is 7%, but rates for mothers under 20 years of age range from 9% for a first-born child up to 15% for a fourth or higher-order child, and the rate for African Americans is 13%. Low-birth-weight babies who survive often face developmental delays and learning disabilities, with significant long-term social and economic costs.

Since its inception in the mid 1980's, the National Institute of Nursing Research has actively advanced research aimed at reducing low birth weight and preterm births. In 1990, NINR began funding a five-year study that is already having an impact at the community level. This randomized controlled study was designed to examine the effectiveness of telephone monitoring in reducing low birth weight and preterm births among high-risk women. The study targeted two groups of low-income pregnant women: African Americans and adolescents. Members of these groups did have access to telephones although they lacked many other resources. The researchers were interested in using low-cost, "low-tech" local phone calls to provide information to and obtain data from the women at regular intervals. The investigators hoped that a series of such calls, placed by registered nurses, would contribute to improved pregnancy outcomes.

The telephone program drew on the investigators' prior studies of predictors of low birth weight and preterm births. Their findings on risk factors such as maternal race, age, weight, marital status, education, smoking history, history of domestic abuse and violence, and physiological indicators such as vaginal pH helped the researchers target their study population and identify questions and topics for productive telephone discussions between participating nurses and patients.

After a home visit to expectant mothers, telephone follow-up was provided by registered nurses one-to-two times per week from the 24th through the 37th week of pregnancy. Nurses assessed signs of preterm labor and discussed via telephone matters such as nutrition, smoking, and drug use, along with other topics of concern to the prospective mothers.

Results

At the end of the study, analysis showed that the low birth weight rate for women in the treatment program was 10.9%, compared to 14.0% for women in a control group. Even more positive results were found specifically for African American women 19 years or older. Their rate of low birth weight infants was dramatically lower than for the corresponding control subjects—11.4% vs. 17.3%. A related outcome, the number of babies delivered prior to term, was even more striking. The difference in the rates of preterm births was 8.7% for women in the treatment program vs. 15.4% for women in the control group.

The program's cost-effectiveness was also encouraging. Expenses for the initial home visit and subsequent phone calls were only \$117 per pregnancy. Hospital savings amounted to \$277 per pregnancy for the highly successful group of African American women 19 years or older. In addition, sizable reductions in costs were expected to accrue for these women and their children beyond delivery, through the elimination or reduction of long-term problems associated with low birth weight.

Finding and keeping minority subjects—often a problem in research studies—proved to be relatively easy in the study, probably because it offered support that pregnant women valued. Of the women invited to participate, 88% agreed, with a mere 0.2% declining to go ahead after the initial home visit, and only 6% to 8% losing contact during the study. Interestingly, the telephone itself proved to be a great advantage in overcoming a common barrier to research with minority populations — cultural differences between researchers and subjects. Although the initial home visits immediately brought white nurses and African American subjects face-to-face, the telephone eliminated visual reminders of differences for the duration of the program. Subjects made no references to the nurses' race in follow-up interviews conducted by an African American.

Into the Community

Stimulated by these positive findings, the investigators began translating the telephone intervention model into four treatment programs — three with participation at the community level by low-income women, and one with nationwide participation by women at all income levels. The investigators adapted the study's protocols to suit the different needs and populations of each setting while ensuring that results were at least as good as those of the original study. These programs treated women from the earliest stages of pregnancy, when changes in maternal smoking, nutrition, or other practices could yield the greatest benefits for babies.

All four programs continue to exist even though Federal funding of the research has ceased. One operates from the clinic where the study pilot was conducted and employs a Spanish-speaking peer counselor to meet the needs of a growing Hispanic population. The second program provides one-on-one telephone support to pregnant African American women by trained African

American volunteers, who have been as successful in reducing smoking during pregnancy as were nurses in the initial study. The third program has adapted the original model to provide telephone support to parents from their child's infancy until his/her fifth birthday. The fourth program, affiliated with a national health maintenance organization, provides prenatal advice by telephone to subscribers all over the country.

Pursuing the Research

Earlier this year, additional analysis of the data showed that the incidence of low birth weight and preterm births increased among African American smokers as their cigarettes per day increased. This association has clear relevance for research on racial and ethnic health disparities in the U.S., especially in light of recent findings that African American smokers' nicotine blood levels are higher than white smokers, despite the fact that African Americans' daily exposure to nicotine is less. Awareness of a correlation between numbers of cigarettes and low birth weight and preterm rates should reinforce smoking cessation efforts by community programs such as those fostered by the study.

This latest analysis also showed that the low birth weight rate among African Americans nonsmokers in the telephone program was much lower than that of their nonsmoking control counterparts—8.5% vs. 12.7%. The difference in preterm rates was just as impressive—7.1% vs. 11.2%. These reductions highlight the dramatic impact that "low-tech" community-based programs of telephone monitoring can have among low-income African American women who have eliminated primary smoking as a risk factor. All these results show the value of this randomized study of telephone monitoring. Efforts are currently underway to replicate the research in a population of military personnel.

SCIENCE ADVANCES

Women's Decision to Participate in Randomized Clinical Trials for Breast and Ovarian Cancer.

Even though heart disease is the leading cause of death for women, the disease that women fear most is breast cancer. Emphasis on early detection and treatment of breast cancer has been the focus of efforts by public and private sector groups as well as by the media. Identification of two genes that are associated with increased risk for breast cancer offered hope that at-risk women would receive care necessary to prevent, diagnose, treat and possibly cure breast cancer. As with many advances in medical technology, ethical dilemmas accompany the advances. One such dilemma is the set of ethical issues surrounding the conduct of randomized clinical trials of interventions to prevent breast cancer in women who are genetically predisposed to developing breast cancer.

The randomized clinical trial is the gold standard used to evaluate the efficacy of a treatment or intervention. One possible barrier to conducting randomized clinical trials in women known to be genetically predisposed to breast or ovarian cancer may be their unwillingness to consent to randomization, since a woman's unique characteristics may make one arm of the clinical trial more preferable than another. The purpose of this study was to assess the feasibility of conducting randomized clinical trials for breast and ovarian cancer risk reduction in women with a family history of breast cancer who were participating in an educational offering about BRCA1/2 genetic testing.

Only a small percentage of women (17-19%) expressed willingness to participate in randomized trials to study risk factor reduction, whereas the majority were willing to participate in non-randomized trials. Women who expressed willingness to participate in a randomized trial were also more willing to undergo prophylactic mastectomy and were more likely to have children. Data suggested the type of prophylactic surgery (mastectomy versus hysterectomy) did not influence the willingness to participate in a randomized trial. The recommendations that physicians give to at-risk women are likely to vary depending on the types of providers. Oncologists were most likely and general practitioners were least likely to recommend randomized studies.

Investigators interested in conducting randomized clinical trials for breast and ovarian cancer risk reduction are likely to encounter difficulty recruiting eligible women. Non-randomized trials are likely to encounter fewer recruiting problems and involve fewer ethical concerns. Therefore, the non-randomized trial is a more viable alternative to randomized trials for evaluating prevention interventions for breast and ovarian cancer when prophylactic surgery is one of the treatments being evaluated. However, the non-randomized design would make the results of such studies more difficult to interpret.

Improving Functional Ability in Nursing Home Residents with Dementia.

Nursing home residents with dementia of the Alzheimers's type as a group have the highest numbers of disabilities. Declines in their cognitive status contribute to these disabilities but other factors which are responsive to intervention may contribute. One factor is nursing staff reinforcement of residents' dependent behaviors. This hinders independent performance of daily activities, which can lead to excess disability beyond that expected from resident's level of cognitive impairment.

Investigators examined one-on-one interventions to improve the ability of cognitively impaired nursing home residents to perform bathing and dressing activities. The intervention involved a research therapist who first determined which bathing and dressing skills were retained by the resident with dementia. Then the therapist structured the physical and social environment to facilitate the resident being able to use those skills.

In response to the rehabilitation intervention, nursing home residents required less physical assistance with bathing and dressing activities; the change was most dramatic for dressing. The decrease in physical assistance was accompanied by an increase in the number of verbal and nonverbal directions given to the resident and an increase in the number of requests the residents made for assistance with performing a task. These improvements in the ability of cognitively impaired nursing home residents were also accompanied by reduced disruptive behaviors and other behavioral indicators of distress such as rattling the bed rail. To achieve these improvements in performing the morning care activities of dressing and bathing doubled from 11 minutes to 20 minutes. These functional gains were attained within 5 days of the start of the interventions and were maintained over three weeks.

When care providers take the time to search for the skills that nursing home residents with dementia have retained, it is possible to reactivate those skills and promote more independent performance of morning care activities without creating disruptive behavior. However, these gains would require additional time on the part of the staff to search for and reward these behaviors.

Family Decision-Making Regarding Life-Sustaining Support among Hospitalized Patients.

United States life expectancy has reached an all time high, but is accompanied by an increase in the number of people living with, and dying from, chronic debilitating diseases such as heart disease, cancer, stroke and chronic obstructive pulmonary disease. While the elderly with chronic illnesses comprise a group one might associate with end-of-life issues, there are other groups at all ages for whom these concerns are important. Coupled with this spectrum of individuals is the increased availability of technologies and treatments that can be used to prolong life and, in some cases, death. Defining when these technologies and treatments shift from life saving interventions to burdensome and futile procedure that negatively impact quality of life has been elusive. When these technologies and treatments become futile, the individuals' families and significant others may be involved in a difficult period of decision-making about how much aggressive treatment to try and when to stop. Conversely there is widespread fear that the only alternative to aggressive treatment is abandonment and suffering.

This study was a multi-method exploration of the factors contributing to stress among family members of patients in whom support was withdrawn. Data were collected from hospital records of people who had life support interventions withdrawn; from their family members at two times; and from care providers who were central to patient care and the decision to withdraw support.

Compared to other types of stressful situations reported in the literature, the level of family stress in the situation of deciding to withdraw life sustaining technology was higher. Three things intensified the stress level: absence of an advance directive, being an ethnic minority and commute distance from the hospital. The factor that most strongly influenced the amount of family stress was whether the patient had an advance directive. The patients' values and preferences were the most important factor in making the decision to withdraw life-sustaining treatment.

This study is one of the first to show that the existence of an advance directive, whether written or verbal, eases the burden for the family and ameliorates the stress associated with the decision to withdraw aggressive treatment. With an advance directive to guide decisions, families were more able to focus on the patients' quality of life and less likely to endorse prolonging life at all costs.

Influences on Weight of Adolescents.

In the twenty plus years since the National Center for Health Statistics compiled its 1976-80 data, the incidence of obesity in children and adolescents has increased approximately six percent. The increased incidence was noted for both boys and girls and for all ethnic groups. This trend is a grave concern since obesity is linked to cardiovascular disease.

Data from various studies provide divergent opinions about the influence of physical activity on obesity in adolescents. The lack of a consistent relationship between physical activity and body weight could be related to several factors not accounted for in these studies, such as socioeconomic status and lack of precision in the measurement of physical activity. The purpose of this study was to examine the effects of physical activity and inactivity on the weight status of adolescents while taking into consideration their socioeconomic status, ethnicity and gender.

In a study of over 2,000 adolescents, investigators discovered that the time adolescents spent doing sedentary activities (such as watching TV and playing video games) did not relate directly to obesity if ethnicity and socioeconomic status were considered. For the girls, being white and having a moderate to high socioeconomic status reduced the risk of being overweight. For the boys, being white and participating in high intensity activities, such as soccer and basketball, for 15 minutes three times per week reduced the boys' risk of being overweight.

The fact that socioeconomic status and ethnicity predict obesity suggests that intervention programs should focus on lower socioeconomic status communities. The study also suggested a clear direction for interventions among adolescent boys, where using strategies to increase participation in high-intensity exercises (soccer, basketball, swimming or running) may protect against obesity. To add this type of physical activity into the busy schedule of adolescents would require the participation of the school to improve physical education programs and intramural experiences. Another option might be to increase community recreation programs that incorporate opportunities for high-intensity physical activities for persons of limited skill. Further research is needed to provide clear direction for the content of such programs for girls. The authors suggest that in girls, dietary habits may be a more important indicator than activity levels in the risk for obesity.

NEW AND EXPANDED ACTIVITIES

Management of Chronic Pain. The prevalence of chronic pain varies widely depending on the location of reported pain and methods of measurement used in the studies, but a prevalence of 10% is a cautious estimate.² Pain is a frequent cause for clinical visits and when combined with depression, pain is a risk factor for suicide.³ There are many categories of patients now receiving treatment who have impaired ability to express their pain, including infants; those for whom English is not a primary language; and those who are cognitively impaired. Additional funds in this research initiative will permit more studies on pain management, including interventions to remove barriers to effective treatment, tools to assess pain in patients unable to verbalize their sensations and effective strategies for underserved populations.

Improving Quality of Life of Patients with Cachexia. Cachexia is a combination of malnutrition-related symptoms frequently present in chronic illnesses such as cancer, cystic fibrosis, AIDS, chronic obstructive lung disease and others. The symptoms of cachexia include weight loss, muscle wasting, shortness of breath and fatigue as well as patient reports of sleep disturbances, listlessness and depression. There is very little research on strategies to prevent, reverse or manage cachexia or how to improve quality of life in these patients. There are a number of promising areas of inquiry available to current science. NINR plans to support researchers who want to find out how to improve nutritional status and quality of life of patients with cachexia.

Informal Caregiving in Non-Institutional Settings. Nearly one in four U.S. families are involved in caregiving for dependent relatives and friends of all age groups, including frail elderly.⁴ Caregivers of older adults may have to deal not only with the physical care problems and helping to run the frail adult's household, but also coping with cognitive problems in the older adult. Caregivers themselves are at risk for poor health, a risk compounded by the stress of caregiving and perhaps their own advanced years. NINR plans to increase research designed to address caregiver needs in differing locations (rural, urban) and in different ethnic and cultural groups. Research is needed to test interventions that provide support for caregivers, and to help the caregivers remain healthy and have improved quality of life. The overall research goal would be to help define what caregivers need to know and practice in order to achieve high quality of life for both caregivers and their dependent family members and friends.

Cancer Prevention Among Minority Populations. National data reveal disturbing trends about specific cancers among racial and ethnic minority communities. For cervical cancer in 1995, for example, the death rate for African-American females (6.7 per 100,000) is more than twice that of white women (2.5 per 100,000).⁵ Many cancers are linked to lifestyle factors of smoking, poor diet, exposure to environmental agents and alcohol, for example. NINR plans to stimulate research to test culturally-sensitive interventions to achieve behavior changes that promote prevention, screening and detection of cancer among ethnic/racial minorities. Examples might include smoking cessation programs, improving dietary patterns and reducing exposure to toxins in the environment. Appropriate screening and other early detection mechanisms have the potential for reducing the disparities in cancer incidence, mortality and survival.

OTHER AREAS OF INTEREST

Training Opportunities in Genetic Research. NINR plans to continue offering the Summer Genetics Institute in 2001, in order to capitalize upon a very successful first offering in the summer of 2000. NINR is pleased with the early evaluation data showing how graduates of the first eight-week training program are implementing their knowledge into their research, education and practice. The need is clearly present to ensure that nurses are well prepared to counsel and care for patients treated with genetic therapy. Participants are expected to engage in research, deliver the highest quality patient care and integrate genetic content into nursing curricula and research.

Addressing National Training Report Recommendations. The recent report of the National Research Council, National Academy of Sciences, "Addressing the Nation's Changing Needs for Biomedical and Behavioral Scientists," had a specific recommendation for NINR. The recommendation was to emphasize research training programs that foster earlier entry into research careers. NINR has developed creative approaches to recruitment of nurses, including minority nurses, into research careers. Given the impetus of the new report's recommendation, NINR efforts in research training are reaffirmed and strengthened. The nursing research community is actively promoting earlier entry by nurses into doctoral programs. Educational programs are underway to further facilitate this goal.

Diversifying Opportunities in Nursing Research Training. An intensified effort to increase the number of rigorously trained nurse scientists is essential to the continued growth of nursing research programs. Nurses often pursue research careers after obtaining advanced practice credentials and several years of clinical experience. Because individuals with advanced clinical backgrounds bring vital questions and skills to the research arena from their practical experience in clinical and community settings, there is much to be gained from designing programs that accommodate their training needs as well. However, in order to take advantage of National Research Service Award (NRSA) training opportunities, nurses must accept substantial reductions in income, just as do physicians, dentists, and other health care professionals.

The NINR intramural program is sponsoring interdisciplinary research training that builds on the unique opportunities offered by the NIH campus. NINR Career Transition Awards (K22s) combine support for research training an appropriate NIH intramural laboratory with subsequent support for independent research in an extramural institution. At the completion of this training, individuals are expected to compete for a research project grant (R01) for the continuation of their work.

NINR Research Focus on HIV/AIDS. The NINR AIDS extramural research program has a primary focus on strategies to manage the serious challenges of living with HIV/AIDS as a chronic illness. The four broad areas of research include: 1) adherence and medical decision making; (2) practicing safer HIV-related sexual behaviors; (3) stress, and coping; and (4) quality of life. Many research projects target vulnerable populations and seek to decrease health disparities. With additional funding in FY 2002, NINR will expand HIV/AIDS research in the areas of prevention strategies, symptom management measures, and adherence to health care

regimens. For example, additional research is needed to determine the most effective schoolbased and other programs targeting adolescents and young adults for the purpose of preventing HIV. Further research is also needed to help patients adhere to the complex medical regimens required for treatment of HIV/AIDS and to adequately manage symptoms such as cachexia in order to enhance the quality of life of persons with HIV/AIDS and their caregivers.

¹ U.S. Department of Health and Human Services (2000). <u>Health, United States, 2000.</u> Table 26. Infant mortality rates and international rankings: Selected countries, selected years, 1960-96, p. 157.

² Verhaak, P.F.M., Kerssens, J.J., Dekker, J., Sorbi, M.J., Bensing, J.M. (1998). Prevalence of chronic benign pain disorder among adults: a review of the literature. <u>Pain, 77, 231-239</u>.

³ Fishbain, D.A. (1999). The association of chronic pain and suicide. <u>Seminars in Clinical Neuropsychiatry</u>, 4, 221-227.

⁴ National Alliance for Caregiving and American Association of Retired Persons (1997). Family Caregiving in the U.S.: Findings from a National Survey. Bethesda, MD: National Alliance for Caregiving.

⁵ U.S. Department of Health and Human Services (1999). Cervical Cancer: Backgrounder. (February 22, 1999: National Cancer Institute).

Budget Policy

The Fiscal Year 2002 budget request for the NINR is \$117,686,000, including AIDS, an increase of \$12,508,000 and 11.9 percent over the FY 2001 level.

A five year history of FTEs and Funding Levels for NINR are shown in the graphs below:



One of NIH's highest priorities is the funding of medical research through research project grants (RPGs). Support for RPGs allows NIH to sustain the scientific momentum of investigatorinitiated research while providing new research opportunities. The Fiscal Year 2002 request provides average cost increases for competing RPGs equal to the Biomedical Research and Development Price Index (BRDPI), estimated at 4.3 percent. Noncompeting RPGs will receive increases of 3 percent on average for recurring direct costs. In FY 2002, total RPGs funded will be 255 awards, an increase of 22 awards over the FY 2001 Estimate, the highest annual total ever awarded.

Promises for advancement in medical research are dependent on a continuing supply of new investigators with new ideas. In the Fiscal Year 2002 request, NINR will support 263 pre- and postdoctoral trainees in full-time training positions. An increase of 10 percent over Fiscal Year 2001 levels is provided for stipends and training-related expenses.

The Fiscal Year 2002 request includes funding for 15 research centers, 51 other research grants, including 11 new clinical career awards, and 3 R&D contracts. The R&D contracts mechanism also includes support for 1 contract for the Extramural Clinical and Pediatric Loan Repayment Programs.

Increased Research Management and Support Funding. NINR will use additional research management and support funds to accomplish three important goals: 1) provide the additional personnel necessary to adequately support our expanding research program; 2) convene expert panels to assist in scientific strategic planning; and 3) provide the financial resources to fund several important technology research initiatives, including software to improve disease reporting and NIH enterprise-wide information technology systems.

As our portfolio moves toward more complex, multi-site clinical studies, increased quality and quantity of scientific staff support is needed to manage effectively and direct the growing research grant portfolios. In addition, we have undertaken information technology research initiatives to improve disease coding and reporting, and thereby improve our ability to disseminate accurate and timely information on the results of our research program to the Department, Congress, the scientific community, and the public.

The mechanism distribution by dollars and percent change are displayed below:





NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

SIGNIFICANT ITEMS IN HOUSE, SENATE, AND CONFERENCE APPROPRIATIONS COMMITTEE REPORTS

FY2001 House Appropriations Committee Report Language (H. Rpt. 106-645)

Item

National Occupational Research Agenda– The Committee encourages NINR to work with the National Institute for Occupational Safety and Health to enhance research in relevant National Occupational Research Agenda priority areas such as Health Services Research, Special Populations at Risk, Low Back Disorders, Musculoskeletal Disorders of the Upper Extremities, and Fertility and Pregnancy Abnormalities. (p. 90)

Action Taken- NINR has a working relationship with several agencies within the Centers for Disease Control and Prevention. NINR hosted staff from the National Institute of Occupational Safety and Health (NIOSH) Director's office in the summer of 2000 to discuss our mutual efforts to stimulate research in areas such as those the Committee noted above. NINR has identified with NIOSH current research portfolio and potential collaborations we can undertake together. Currently, NINR is funding several studies in health services research, as well as studies in risk reduction for major diseases. Related to the NIOSH priority area of Fertility and Pregnancy Abnormalities, one area of potential collaboration capitalizes on NINR's position at the cutting edge of emerging genetics and genetics therapy research. We look forward to continuing the working relationship with NIOSH.

Item

Nursing Interventions for Psychiatric Populations– The Committee encourages NINR to collaborate with NIMH and expand research in this area through all available mechanisms, as appropriate, including sponsoring a workshop to identify areas of research and interventions that directly correlate to enhance patient care. (p. 90; also p. 75)

Action Taken- With the leadership of NIMH, NINR has collaborated in the development of a plan for a workshop to be offered within FY2001 for the psychiatric nursing community. The workshop plan has been shared with the leadership of the two major national psychiatric nursing organizations who are confident the plan addresses important needs such as those expressed by the Committee. NINR and NIMH are preparing specifics for the plan and are networking with the psychiatric nursing national organizations to widely disseminate information about the workshop in a timely manner.

Item

Pressure Ulcers– Seventy-three percent of expenditures for pressure ulcer treatment are for nursing care. Technology developed through the SBIR program offers potential for treating and preventing pressure ulcers in long-term care facility patients. The Committee encourages NINR to advance research in this area through all available mechanisms, as appropriate. (p. 90)

Action Taken- NINR has a rich history of funding research in the area of pressure ulcers, including funding Small Business Innovation Research projects. NINR will continue to fund meritorious applications using a variety of mechanisms to address research or research training in this important area of science and practice.

Item

Web-Based Technology– The use of computer technology has the potential to improve the coordination and delivery of care among persons with disabilities and severe chronic conditions such as spinal cord injury, diabetes and arthritis, and reduce transaction costs associated with traditional care delivery mechanisms. The Committee encourages NINR to conduct research in this area to demonstrate the effectiveness of an e-health tool for nurse case managers. (p. 90/91).

Action Taken- NINR has funded important research in telehealth, which is an area of science that incorporates the use of communications technologies to provide and support health care at a distance. NINR recently released a Program Announcement which will be effective for three years, entitled "Telehealth Interventions to Improve Clinical Nursing Care". It is NINR's intent to stimulate clinical research on innovative nursing telehealth interventions, particularly their use among a wide variety of clinical situations, diverse patient populations and different clinical settings. NINR anticipates a good response to this Program Announcement, which directly addresses the Committee's suggestion.

NATIONAL INSTITUTES OF HEALTH

National Institute of Nursing Research

SIGNIFICANT ITEMS IN HOUSE, SENATE, AND CONFERENCE APPROPRIATIONS COMMITTEE REPORTS

FY2001 Senate Appropriations Committee Report Language (S. Rpt. 106-293)

Item

New research opportunities in nursing research– The Committee encourages the Institute to take advantage of significant new research opportunities in the following areas: enhancing adherence to diabetes management behaviors; biobehavioral research for effective sleep in health and illness; prevention of low birth weight in minorities; improved care for children with asthma; collaborative clinical trials for adherence, decision-making, and managing symptoms in AIDS and cancer; and expanded opportunities for pre- and postdoctoral training in nursing research at schools of nursing across the country. (p. 158)

Action Taken- NINR is pleased to report that the science areas identified by the Committee are being promoted as areas of opportunity. NINR anticipates applications from the recent research initiatives published that directly relate to the areas of science above. Additionally, NINR is pleased to sponsor or cosponsor other research initiatives which will support pre- or postdoctoral fellows:

a senior fellow award program announcement; a postdoctoral award in genetics-related research; predoctoral training in the neurosciences; a minority research scientist development award; a successful program for research supplementation for underrepresented minorities. Other career development awards are being maintained to meet the diverse research needs of the nurse public.

Item

Nursing Interventions for Psychiatric Populations– The Committee is concerned over the lack of resources for outcomes research focused on nursing interventions for psychiatric populations. The Committee urges the NINR and the NIMH to jointly sponsor a workshop with the psychiatric nursing community to identify areas of research and specific questions directed at interventions in psychiatric populations that directly correlate to enhanced patient care. This workshop would lead to a joint request for applications by the NINR and the NIMH. (p. 158)

Joint workshop between NINR and NIMH– The Committee is concerned regarding the lack of resources for outcomes research focused on nursing interventions for psychiatric populations. The Committee urges the NINR and the NIMH to jointly sponsor a workshop with the psychiatric nursing community to identify areas of research and specific questions directed at interventions in psychiatric populations that directly correlate to enhanced patient care. (p. 165/166)

Action Taken- With the leadership of NIMH, NINR has collaborated in the development of a plan for a workshop to be offered within FY2001 for the psychiatric nursing community. The workshop plan has been shared with the leadership of the two major national psychiatric nursing organizations who are confident the plan addresses important needs such as those identified by the Committee. NINR and NIMH are preparing specifics for the plan and are networking with the psychiatric nursing national organizations to disseminate information about the workshop in a timely manner. It is expected that the outcome of the workshop will be a number of applications for research project funding which will perform well in the scientific review process.

Item

Volcanic Emissions– The Committee continues to be concerned about the public health aspects of volcanic emissions (VOG) in Hawaii and urges the Institute to collaborate with the National Institute of Environmental Health Sciences in developing a multidisciplinary approach to this problem. (p. 158)

Action Taken- NIEHS recognizes the importance of obtaining information related to potential adverse health effects of VOG and of assessing other environmental health concerns of particular significance to the citizens of Hawaii and to Native Hawaiians. NIEHS has been addressing this concern since 1996. Since that time, in conjunction with CDC, NIEHS has supported preliminary exposure assessment and epidemiology studies conducted collaboratively by researchers at the Hawaii Department of Health (HI DOH) and the NIEHS Environmental Health Sciences Center at the University of Southern California. The objectives of this project are to: support HI investigators in the preparation, planning and performance of a field study to assess respiratory health effects of VOG; enhance the capabilities of the HI DOH in epidemiologic assessment and hazard investigation; and provide support in environmental health research to HI DOH. Exposure monitoring stations are currently deployed as part of the first phase of the VOG health study. The USC NIEHS Center has provided training of HI DOH personnel in environmental epidemiology. Such work may establish whether or not VOG adversely impacts human health, thus providing the basis for further research activities. NIEHS will continue to consult with NINR, CDC, and other agencies to coordinate our efforts on this problem.