# NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS (NIDCD)

## Comprehensive Strategic Plan and Budget to Reduce and Ultimately Eliminate Health Disparities

#### NIDCD MISSION/VISION STATEMENT

The mission of the National Institute on Deafness and Other Communication Disorders (NIDCD) is to conduct and support basic and clinical research and research training in the normal and disordered processes of hearing, balance, smell, taste, voice, speech, and language. Basic and clinical research focused on understanding the normal processes and disorders of human communication are motivated both by intrinsic scientific interest and importance to the health of the Nation.

#### OVERVIEW OF NIDCD STRATEGY FOR ADDRESSING HEALTH DISPARITIES

It is estimated that one of every six Americans, people of both genders and of all ages and races, experiences some form of communication disorder (e.g., hearing impairment, dizziness, balance problems, smell and taste disorders, and voice, speech or language disturbances). Such disorders often compromise social, emotional, educational and vocational aspects of an individual's life. The cost of these disorders in terms of quality of life and unfulfilled potential is substantial.

In preparation for developing a Strategic Plan on Reducing Health Disparities on human communication disorders that impact all levels of the American population, the NIDCD sought broad input from the NIDCD Advisory Council and Board of Scientific Counselors. In addition, the NIDCD solicited comments from 170 of its constituent groups, including scientific and professional organizations that have interest in deafness and other communication disorders. Several research opportunities to understand the basis for health disparities within the purview of NIDCD were identified

## **AREA OF EMPHASIS 1:**

Advance Understanding of the Development and Progression of Diseases and Disabilities That Contribute To Health Disparities

Rationale and Priority of Objectives: Area of Emphasis 1

<u>Objective 1.1</u>: Research to Explore the Possibility of a Genetic Basis for Increased Susceptibility to Otitis Media in Native Americans

Otitis media (OM), or middle ear infection, is the most common cause for visits by children to physicians for acute illness, costing several billion dollars annually in the United States. In addition to the discomfort and risk of more serious infection such as meningitis, OM is also associated with disabilities such as hearing deficits, reading disorders, and language delays. The disorder is reported to occur at a disproportionately high rate among Native American children. A number of papers have been written about OM and Native Americans, some suggesting that there are anatomical differences between Native Americans and other Americans in the anatomy of the eustachian tube. It has also been reported that there are differences in the rate of OM among the various Native American tribes.

#### Action Plan, Objective 1.1:

A recent scientific study reported a complex genetic basis for susceptibility to otitis media. Native Americans were not included in this study, leaving open the possibility that allelic variants of one or more genes may confer susceptibility to otitis media in Native Americans. OM, particularly recurrent serous otitis media, deserves attention because of the particularly high prevalence of the disease and associated disabilities among Native Americans. The NIDCD conducted a workshop in November 2000 to discuss new approaches for analysis, treatment and prevention of OM. Some of the recommendations from the workshop have resulted in a Program Announcement (PA) calling for development of novel diagnostics for the identification of specific OM-causing pathogens in patients and will be published in October 2002. A separate Request for Applications (RFA) will be published shortly thereafter calling for research on specific pathogenic mechanisms that trigger OM, genomic approaches to OM vaccine development and studies of genomic markers in individuals that might identify a predisposition to chronic OM infections.

#### Estimated Timeline, Objective 1.1:

FY 2002

FY 2003

FY 2004

FY 2005

FY 2006

## Performance Measures, Objective 1.1:

- Publish PA and RFA for new research on OM.
- New studies resulting from the planned PA and RFA to significantly increase research on this important public health need.
- Studies examining the hypothesis that allelic variants in one or more genes may underlie the increased susceptibility of Native Americans for OM.

#### Outcome Measures, Objective 1.1:

• Examine research outcomes to determine if there is a genetic basis for susceptibility to OM in Native Americans.

## Objective 1.2: Study the Epidemiology of Otitis Media in Native Americans

#### Action Plan, Objective 1.2:

Although Native Americans have a high prevalence of chronic otitis media, prospective studies of OM among Native American infants and young children of this group are sparse. The goals of this study are to understand the epidemiology of otitis media and hearing loss among Native Americans from birth to age two, and define the relative importance of known and new risk factors in this population. A community program assessment of services has been conducted regarding breast feeding promotion and support, tobacco control, and nutrition for prenatal infants and mothers. The findings of this assessment indicate that intervention programs should focus on tobacco control, as this is a significant risk factor for OM in this population and there appears to be a gap in services addressing infant exposure to parental smoking.

### Estimated Timeline, Objective 1.2:

FY 2002

FY 2003

FY 2004

FY 2005

FY2006

## Estimated Timeline B Intervention & Outreach Initiatives, Objective 1.2:

FY 2002

FY 2003

FY 2004

FY 2005

FY 2006

#### Performance Measures, Objective 1.2:

• New research on the basic and behavioral aspects of OM, especially in the Native American population.

#### Outcome Measures, Objective 1.2:

• Use research outcomes to develop intervention and outreach efforts to reduce the burden of otitis media in Native Americans caused by risk factors identified in the present study.

#### **AREA OF EMPHASIS 2:**

Develop New or Improved Approaches for Detecting or Diagnosing the Onset or Progression of Diseases and Disabilities That Contribute To Health Disparities

Rationale and Priority of Objectives: Area of Emphasis 2

## Objective 2.1: Develop Language Tests for Non-Standard English

Hearing and Language Disorders. In this age of information, communication and technology skills are central to a successful life for all Americans, and the labor force of the 21st century will require intense use of these skills. However, for about one in six Americans with communication disabilities, and their families who support them, facing each day can be a challenge. The simple acts of speaking, listening, of making their wants and their needs understood are often impossible. Hearing and language disorders can exact a significant economic, social, and personal cost for many individuals. A more complete understanding of the scientific mechanisms underlying normal communication and the etiology of human communication disorders is needed.

#### Action Plan, Objective 2.1:

As the U.S. becomes more culturally, racially and linguistically diverse, it is becoming increasingly difficult to discriminate between language disorders and language differences in children. Problems in language assessment arise because the majority of currently available measures are designed for identifying speech and language problems in Standard English speakers. Many children of multicultural populations are often misdiagnosed as language impaired because culturally appropriate language assessment instruments or procedures are unavailable. In addition, other children from multicultural populations who have genuine language disorders that are in need of remediation may go unrecognized.

In response to this need, the NIDCD is supporting projects to develop language tests for non-standard English, specifically for children who speak Black English and for bilingual Hispanic children. Investigators are collecting cross-sectional data on language abilities in normally developing four- to six-year-old speakers of Black English and bilingual Hispanic children whose primary language is not English or is a non-standard form of English. These data are aimed at developing items for a language assessment instrument or procedure that could be used to differentiate between language impairment and normal language development in these two populations.

### Estimated Timeline, Objective 2.1:

DC-8-2100 DC-8-2104

FY 2002

FY 2003

#### Estimated Timeline for New Initiative, Objective 2.1:

FY 2004

### Performance Measures, Objective 2.1

• Develop and disseminate language assessment instruments and procedures that will distinguish between language disorders and language differences in Hispanic and African American children.

#### Outcome Measures, Objective 2.1:

• Support additional research to determine the effectiveness of the new language tests by monitoring the rate of increase or decrease of language disorders in Hispanic and African American children.

## <u>Objective 2.2</u>: Determine the prevalence of hearing loss and problems with balance in the adult U.S. population and for groups based on race/ethnicity or economic disadvantage.

Hearing Loss and Balance Problems. An estimated 28 million people in the United States are deaf or hearing impaired and 6 million people report having problems with balance or dizziness lasting three months or longer. Presbycusis, the loss of hearing associated with aging, affects about 30 percent of adults 65 years of age and older. Chronic imbalance/dizziness has been reported in nine percent of seniors. As the population ages and lives longer, the number of Americans affected is increasing. Prevalence rates of adult hearing loss, based on health examination data, have not been collected since the First National Health and Nutrition Examination, 1971-1975. Although health disparities among adults with hearing loss (and chronic balance problems) are suspected, there are no currently available data.

#### Action Plan, Objective 2.2:

A six-year study of hearing levels in the U.S. began in April 1999, the Fourth National Health and Nutrition Examination Survey (NHANES IV). NIDCD is funding hearing and balance testing through an Inter-Agency Agreement with the National Center for Health Statistics (NCHS). NIDCD collaborated with the National Institute for Occupational Safety and Health (NIOSH) and outside consultants to develop the exam protocol. Exams are conducted on subjects living in randomly selected communities, which over the course of the study will provide a representative sampling of the United States. Balance testing is accomplished using a modified Romberg test of standing balance. Air conduction, pure-tone hearing thresholds are obtained in sound-treated booths. Also, household questionnaires on problems with hearing (including tinnitus) and exposures to occupational and leisure noise and other risk factors are administered as part of a larger multifaceted examination and interview survey. Hearing and balance exams will be completed on about 6,000 adults, with over sampling of African American and Hispanics (Mexican Americans) to ensure reliable prevalence estimates. The sample is large enough to produce prevalence estimates by educational level, family income, and other measures of economic disadvantage.

## Estimated Timeline, Objective 2.2:

FY 2002

FY 2003

FY 2004

#### Performance Measures, Objective 2.2:

• Continue collaboration with the NCHS and NIOSH to develop exam protocols to test for hearing and balance disorders in minority populations surveyed in NHANES IV.

## Outcome Measures, Objective 2.2:

• Analyze results of the survey to determine if certain racial or ethnic groups are at higher risk for developing disorders of hearing and balance.

## <u>Objective 2.3</u>: Determine the prevalence of use of hearing aids in the U.S. population as well as the cause, if known, and age at onset of hearing loss or deafness.

#### Action Plan, Objective 2.3:

The National Health Interview Survey (NHIS) 2002 will include additional questions on hearing loss and use of hearing aids to address important health issues. NIDCD is funding questions on use of hearing aids and the cause and age at onset of hearing loss or deafness through an Inter-Agency Agreement with NCHS. This information will be important for monitoring the hearing health of the U.S. population with respect to Healthy People 2010 goals. The questions will be administered to one sample person in each randomly selected household for a total sample size of about 40,000. Because of the representative study design and comparatively large sample size, prevalence rates will be available by race and ethnic group and by family income, educational level, and other measures of economic disadvantage.

#### Estimated Timeline, Objective 2.3:

FY 2002

FY 2003

#### Performance Measures, Objective 2.3:

- Continue collaborative effort with the NCHS to complete data collection.
- Determine the prevalence of hearing loss and hearing aid use among racial and ethnic groups.

## Outcome Measures, Objective 2.3:

• Plan a follow-up clinical trial with the Department of Veterans Affairs to examine hearing aid use in another large sample population to compare the prevalence of hearing loss and hearing aid use among racial and ethnic groups.

#### **AREA OF EMPHASIS 3:**

Expand Opportunities in Research Training and Career Development For, and Provide Research Supplements To, Research Investigators From Minority and Other Special Populations Experiencing Health Disparities

Rationale and Priority of Objectives: Area of Emphasis 3

## <u>Objective 3.1</u>: Recruit and Retain Individuals from Underrepresented Groups to Careers in Research in Human Communication Through In-depth Experiences at NIDCD

## Action Plan, Objective 3.1:

In collaboration with the NIH Office of Research on Minority Health (ORMH), the NIDCD Partnership Program was implemented to provide comprehensive research and training opportunities for qualified underrepresented minorities in biomedical and behavioral research. This research and training demonstration program began in 1994 with four academic centers with large enrollments of minority persons: The Morehouse School of Medicine/Atlanta University Complex, the University of Alaska, the University of Puerto Rico, and Gallaudet University.

The program provides an opportunity for exchange of personnel between the NIH and the academic centers. Each center collaborates with the NIDCD in developing a plan for that center and for the students, faculty, or staff of the institution. This program not only provides research training opportunities for students in NIDCD laboratories, but also provides career development for faculty and administrators at the academic centers in the program.

## Estimated Timeline, Objective 3.1:

FY 2002

FY 2003

FY 2004

FY 2005

FY 2006

#### Performance Measures, Objective 3.1:

 Monitor effectiveness of the Partnership Program by having NIDCD staff serve as mentors to each program participant. To date, there have been 80 participants in the Partnership Program, including faculty and administrators who have come to NIDCD to learn about grants review, management, and administration through workshops as well as short-term placements in grants offices.

## Outcome Measures, Objective 3.1:

• Expand the program in 2001 to include students, faculty and administrators from all undergraduate, graduate, or medical schools in the United States. The target

populations for the program remain the same -- the underrepresented, the disadvantaged, and persons with disabilities. This expanded effort will increase opportunities for individuals beyond the initial partner affiliates.

## Objective 3.2: Support the Minority Supplements Program

#### Action Plan, Objective 3.2:

The Research Supplements for Underrepresented Minorities program is another mechanism used by NIDCD to recruit minority researchers. Expanding upon the support provided by currently funded research grants, the supplement provides a means by which promising minority research trainees can gain training to enhance their research careers. Principal Investigators (PIs) currently being funded by NIDCD, who are interested in mentoring a minority student or junior faculty member, are encouraged to consider developing a supplemental application to their existing grant. The NIDCD is proposing a potential new initiative to assess the Institute's Research Supplements for Underrepresented Minorities Program. The NIDCD has had a very active minority supplements program over the past several years and, in collaboration with NIH National Center on Minority Health and Health Disparities, plans to evaluate participant success in pursuing careers in biomedical research. The results of this assessment will help to determine predictors for success.

## Estimated Timeline, Objective 3.2:

FY 2002

FY 2003

FY 2004

FY 2005

FY 2006

## Estimated New Initiative Timeline, Objective 3.2:

FY 2002

FY 2003

FY 2004

FY 2005

FY 2006

#### Performance Measures, Objective 3.2:

• Continue an annual evaluation of the number of minority supplements awarded and the type of students trained to determine effectiveness of program. There is a national need for additional minority scientists in fields of basic, clinical, and health services research. The NIDCD has used this funding mechanism to initiate research training and career development opportunities for individuals, in particular minority individuals, interested in research on human communication sciences and its

disorders. The Institute is committed to increasing support for this important program.

## Outcome Measures, Objective 3.2:

• Evaluate the future success of program participants in pursuing careers in biomedical research in human communication disorders.

#### **AREA OF EMPHASIS 4:**

## **Develop Targeted Public Health Education Programs**

Rationale and Priority of Objectives: Area of Emphasis 4

## Objective 4.1: Increase Public Awareness and Prevent Noise-Induced Hearing Loss

Ten million Americans have already suffered irreversible damage from noise, and 30 million are exposed to dangerous levels of noise each day. Exposure to harmful sounds causes damage to the sensitive hair cells of the inner ear, eventually affecting hearing. These structures can be injured by noise in two different ways: from an intense brief impulse, such as an explosion from a firecracker; or from continuous exposure to noise, such as in a woodworking shop.

#### Action Plan, Objective 4.1:

The WISE EARS! Campaign was initiated on July 4, 1999 and now includes a Coalition of more than 80 organizations of workers, employers, health and medical professionals, advocates for children and older Americans, teachers, parents, children, unions, industry, federal, regional and local government agencies and institutes, and the general public. The Wise Ears! Campaign has been published nationwide in over 1,000 newspapers with an estimated readership of 91 million. The campaign is designed to reach minority individuals as identified by specific occupational or recreational risk. Future plans include increasing the Coalition membership and expanding the campaign to all 50 states and territories.

In addition, a special outreach effort is underway to reach industrial workers, Hispanic/Latino/Latina individuals, and a special effort to reach Native American teenagers in work and recreational environments that are damaging to their hearing. Many materials are available in Spanish. This is a collaborative effort with the NIH Office of Hispanic Communication.

## Estimated Timeline, Objective 4.1:

FY 2002

FY 2003

FY 2004

FY 2005

FY 2006

## Performance Measures, Objective 4.1:

- Develop a first phase evaluation of the WISE EARS! Campaign in industrial workers, Hispanic/Latino/Latina individuals, and Native American youths to determine the effectiveness of outreach activities on noise-induced hearing loss to minority populations.
- Expand the campaign to a national level.

## Outcome Measures, Objective 4.1:

• Expand evaluation of the effectiveness of disseminating information on noise-induced hearing loss to other minority populations.

# NIDCD Health Disparities Budget (Dollars in Millions)

	FY 2002			FY 2003		
Institute / Center	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
NIDCD	\$1.90	\$1.50	\$0.00	\$2.00	\$1.70	\$0.00