FINAL REPORT

Evaluation Study
NIDCD Working Group on Epidemiology and Data Sources for Human Communication, Conditions, Diseases, and Disorders

December 2002
I. BACKGROUND AND PURPOSE

The National Institute on Deafness and Other Communication Disorders (NIDCD), one of the institutes of the National Institutes of Health (NIH) within the Department of Health and Human Services, supports and conducts research and research training on the normal and disordered processes of human communication: hearing, balance, smell, taste, voice, speech, and language. NIDCD develops and disseminates information, based upon scientific discovery, to the public.

NIDCD is considered an important, authoritative source on diseases and disorders of human communication and strives to present accurate information at all times. This has been a challenge in the area of incidence and prevalence data within the topic areas of hearing, balance, smell, taste, voice, speech and language. Many numbers provided to the professional and public communities are based on best available estimates. In order to clarify what data are significant, which need further corroboration, and to ensure that all of the institute's constituents have access to data sets that are used in these estimates or in support of information disseminated, NIDCD's Office of Health Communication and Public Liaison (OHCPL) applied for and successfully competed for evaluation set-aside funding from the Office of Evaluation in the Office of Science Policy and Planning.

The Chief of OHCPL, the Director of the Division of Extramural Research, and the Chief of the Epidemiology and Data System Management Branch of the NIDCD agreed to collaborate on developing an evaluation strategy and on designing a project concept that would allow for improved dissemination of the best available data with the help of a panel of experts and support of data searches internally to NIH and by contract.

The purposes of this document are to: (1) describe the evaluation process NIDCD used to gather and assess epidemiological data on human communication diseases and disorders; (2) demonstrate how NIDCD's process can be utilized to present epidemiological data to a wide audience; (3) suggest how this process can be used to gather further information on diseases and disorders in outyears.

The remainder of this document is organized into two sections. Section II describes the process used to gather epidemiological data, and Section III provides a summary of the findings and recommendations for future activities. Appendices A through G are included to provide additional supporting information.

*Appendix A lists the topic areas in which NIDCD has sole responsibility, as well as shared or secondary responsibility for providing health information to the public.*
II. PROCESS

This section describes the process used to gather epidemiologic data. Along with background information, this section provides information on how experts in various areas of communication disorders were identified and convened, how the literature searches were conducted, and how the process evolved over time.

1. BACKGROUND

The overarching intent of this project was to ensure that NIDCD's constituents receive the highest quality epidemiologic data through fact sheets, the NIDCD's public information office (OHCPL), and provided by OHCPL to the NIDCD's Web site. Historically, informational data had been provided based on existing printed estimates from a wide variety of sources. Data were not provided based upon consistency of definition or terminology nor across peer-reviewed literature. Many of the best professional estimates were the result of a national strategic planning effort held by the fledgling NIDCD in 1989 at the founding of the Institute.

This meant that the NIDCD needed to reach consensus regarding the availability, validity, and the reliability of epidemiologic data currently published in the field of human communication processes and disorders. NIDCD OHCPL and Division of Extramural Research (DER) staff concluded that in order to address this problem, a working group would be called to review data and provide strategies for a long term effort to ensure the quality of information provided to professionals and the public.

2. IDENTIFYING AND CONVENING EXPERTS

To accomplish this task, the NICDC first identified five experts in the field of communication disorders. These individuals were chosen based on their:

(1) area(s) of scientific expertise coupled with experience in epidemiological study;
(2) familiarity with NIDCD and its research and research communities;
(3) access to other experts in the field.

Additionally, under two mechanisms, a project request from the NIH Clinical Center Library and a contract #263-01-D-0157, searches were initiated of both the medical and social science literature. These activities are described in detail below. A timeline of events is provided in Appendix B.

On December 14, 2001 the identified experts met by telephone conference call. Participants included:
In addition, NIDCD staff participated in the evaluation process:

Marin P. Allen, Ph.D., Chief, Office of Health Communication and Public Liaison
Robert A. Dobie, M.D., Director, Division of Extramural Research
Howard Hoffman, M.S. Chief, Epidemiology and Data Systems

See Appendix C for participant information.

The charge for the initial telephone conference meeting in December 2001 was to:

(1) consider the scope of the problem;
(2) identify additional expertise or members if needed;
(3) consider the scope of the definitions to be used in complex subject areas (e.g., speech disorders/hearing loss);
(4) plan for working group meeting to be held in 2002.

The process of conducting the literature searches is described below.

3. CONDUCTING LITERATURE SEARCHES

After receiving direction from the experts and to prepare for the next phase of the work, the NIDCD commissioned two literature searches: one through the National Institutes of Health Clinical Center Library staff using the National Library of Medicine resources and that focused upon peer-reviewed medical literature. A second search was undertaken through a consulting firm with expertise in social science literature that focused on peer-reviewed social science literature not captured in the medical literature data bases but with relevance to some areas of human communication research within the NIDCD's areas of responsibility. The parameters for both of these literature searches were the same:

- Topics were based upon primary and shared responsibility as listed in the NIH Information Index (see Appendix A):
  - Search of peer reviewed, current literature would include only years 1997-2002;
  - Review articles were to include years 1992-2002.

For both searches, the process was, intentionally, matched. Based on the NIDCD's areas of primary and shared or secondary responsibility, as well as high priority areas for the Institute, over 100 terms related to communication processes and disorders were searched using the NLM collections (MedLine and companion databases) and the PsychInfo database.
Abstracts of publications were included in the collected data if they dealt with epidemiologic aspects of communication processes or disorders including incidence, prevalence, gender difference, risk or cost or burden of disease. The focus was mainly on empirical studies, but publications that were more descriptive in nature, or those that discussed epidemiological issues were also included in order to give the panel the broadest possible access to available material.

Publications were excluded if they focused on issues unrelated to epidemiology, such as personal stories or case studies. The search strategies for each area of responsibility are listed in Appendix D. These topic areas were clustered into three categories: (1) hearing and balance, (2) smell and taste, and (3) voice, speech and language.

It was originally intended that the NIDCD experts would be convened in a face-to-face meeting/workshop to review the literature searches and reach consensus regarding which publications to include in the final list of literature to be made available on the NIDCD Web site. Additionally, the group was to consider potential mathematical modeling strategies and the possibility of conducting a meta-analysis of the relationship between areas in the two searches. The mathematical model was to have been grounded in the existing literature, and was intended to allow the NIDCD to project and to map trends over time.

4. EVOLVING PROCESS

The volume of material identified in each area dictated that individual conference calls would be more effective. After reviewing the material, it was determined that it would be premature to develop mathematical models and meta-analyses across the areas. The experts recommended to NIDCD that it is more important to first identify the key literature and get this information out to the public before considering other forms of analysis.

The contractor prepared master notebooks and data files of all materials and NIDCD sent them to the experts. These included CD-roms of the two master searches, representative, results sampling of abstracts from key topics in each scientist's area(s) of expertise, and current publicly used statistics in all areas (Appendix E). Additionally, the experts received electronic copies of search strategies used for both the biomedical and the biobehavioral literature in order to compare the strategies with samples of the results to assure that the search strategies were sound.

The OHCPL Chief and DSMB Chief independently reviewed all abstracts to assess if the searches had been comprehensive and appropriate. After the review, they discussed the results and dealt with one specific issue—abstracts that were from international sources. It was decided that these English language studies should be included for the expert panel, especially as some of the longitudinal Scandinavian studies were of particular value.
During the conference calls, the experts were to review the literature searches and assess if the identified literature covered the important aspects of the topic area. Specifically, the NIDCD experts would evaluate the citations to determine if they were credible epidemiological references on communication diseases and disorders in the NIDCD’s purview. Additionally, they would identify any seminal literature that was absent from the literature searches.

These citations and the corresponding articles would be made available through the NIDCD Web site by live links. Each expert would be responsible for writing a brief state-of-the-art summary of her/his focus area, and the citations would be hyperlinked to these summaries. With additional material from OHCPL staff, the content paragraphs were produced and key articles identified. Appendix F includes the resulting introductory paragraphs, data sources that include key and chapter resources, and a pre-packaged search strategy for topics from the information index to allow an individual to modify and to conduct his or her own searches. Work has begun on linking to data sites in the federal government to provide another substantive resource.

Once this process of identifying and reviewing literature is vetted by NIDCD, it is hoped that the process can serve as a guide to ensuring that NIDCD’s constituents and the general public will continue to receive the highest quality epidemiological information available and provide a model for other institutions to review public data.
III. Summary and Recommendations

Panel experts praised the process and suggested that two key items were important needed additions to the materials identified in the search:

- Book chapters, are an item that is not included in either MedLine or in the social science search engine, but key to having significant, thoughtful data available.

- Key articles that are out of the range of 5 years for peer-reviewed articles and 10 years for review articles need to be included. Criteria for these key articles include usefulness to the field as evidenced by multiple citations in current literature. Each expert will provide a list of the seminal articles for inclusion in a "key articles" section of the Web site."

In seeking to clarify what data are significant, which need further corroboration, and to ensure that all of the institute's constituents have access to data sets that are used in these estimates or in support of information disseminated, the NIDCD undertook a unique and challenging project. Along with the identification of chapters not included in either literature search, and the absence of some key articles, there were a number of other findings resulting from this project. They are as follows:

The amount of available epidemiologic information varies by scientific topic and within topic areas.

- Some key words used in the literature searches may not be appropriate for some relevant articles. Some experts noted that traditional epidemiological language (e.g., incidence and prevalence) may not be the key word used in some of the literature on communication processes and disorders.

- In some areas of communication disorders, identifying critical articles is difficult because the terms are not always clearly defined. For example, there is little uniformity in the definition of hearing loss or deafness, making it difficult to identify important and comparable studies without expert input.

Based on the results of this process, it is recommended that the NIDCD consider the following actions as it continues to strive to provide its constituents with the most up-to-date and significant information available in the field of human communication processes and disorders.

- Include key articles in order to help others perform searches.

" Dr. Allen committed to including the chapter citations and in the Combined Health Information Database (CHID) (Appendix G) so that searches through PubMed or directly through CHID would make these data available.
Pursue the development of a mathematical model (as more data become available) to allow the NIDCD to map trends over time.

Conduct a meta-analysis (as more data become available) to allow for the synthesis of available data, the identification of gaps in the data, and possible new data.

Place key literature, including chapters outside the scope of the two literature searches, in the CHID database (Combined Health Information Database) supported by the OHCPL through the NIDOCID Clearinghouse. This will allow the data to be captured through PubMed.

Update the data and information available on the NIDCD's Web site continuously to ensure the best possible data are available to NIDCD scientific and public consumers.

As the report is being prepared, the new generation of the NIDCD complete Web site is about to be launched. The first sections of the new data sources are being included within the new site, with predicted growth of the site over the next several months and years continued renewal of the site throughout its use. Depending upon cost and time, some or all of the resources will be linked to articles beyond the initiating search articles, chapters and "key" resources.
### APPENDIX A

#### NIDCD HEALTH & DISEASE AREAS

<table>
<thead>
<tr>
<th>AREAS WHERE NIDCD HAS SOLE RESPONSIBILITY</th>
<th>AREAS WHERE NIDCD HAS SHARED OR SECONDARY RESPONSIBILITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ageusia</td>
<td>Otitis Externa</td>
</tr>
<tr>
<td>Anosmia</td>
<td>Otosclerosis</td>
</tr>
<tr>
<td>Aphasia</td>
<td>Ototoxic Drugs</td>
</tr>
<tr>
<td>Aphonia</td>
<td>Parosmia</td>
</tr>
<tr>
<td>Articulation Disorder</td>
<td>Perilymph Fistula</td>
</tr>
<tr>
<td>Assistive Devices</td>
<td>Pheromone</td>
</tr>
<tr>
<td>Auditory Brainstem Implant</td>
<td>Positional Vertigo</td>
</tr>
<tr>
<td>Auditory System</td>
<td>Sensorineural Hearing Loss</td>
</tr>
<tr>
<td>Augmentative Devices</td>
<td>Sign Language</td>
</tr>
<tr>
<td>Aural Rehabilitation</td>
<td>Smell (Disorders)</td>
</tr>
<tr>
<td>Autoimmune Deafness</td>
<td>Specific Language Impairment</td>
</tr>
<tr>
<td>Balance Disorders</td>
<td>Stuttering</td>
</tr>
<tr>
<td>Benign Paroxysmal Positional Vertigo</td>
<td>Sudden Deafness</td>
</tr>
<tr>
<td>Captioning</td>
<td>Syndromic Hearing Impairment</td>
</tr>
<tr>
<td>Central Auditory Processing Disorders</td>
<td>Taste Disorders</td>
</tr>
<tr>
<td>Chemosensory Disorders</td>
<td>Temporal Bone Bank</td>
</tr>
<tr>
<td>Cholesteatoma</td>
<td>Throat Disorders</td>
</tr>
<tr>
<td>Cochlear Implant</td>
<td>Tinnitus</td>
</tr>
<tr>
<td>Communication (Normal)</td>
<td>Tympanoplasty</td>
</tr>
<tr>
<td>Cued Speech</td>
<td>Velocardiofacial Syndrome</td>
</tr>
<tr>
<td>Deaf-Blindness</td>
<td>Vestibular Neuronitis</td>
</tr>
<tr>
<td>Deafness</td>
<td>Vestibular System</td>
</tr>
<tr>
<td>Decibel Information</td>
<td>Vhrotactile Aids</td>
</tr>
<tr>
<td>Disequilibrium</td>
<td>Vocal Cord Paralysis</td>
</tr>
<tr>
<td>Dizziness</td>
<td>Voice Disorders</td>
</tr>
<tr>
<td>Dysfluency</td>
<td>Waardenburg Syndrome</td>
</tr>
<tr>
<td>Dysgeusia</td>
<td></td>
</tr>
<tr>
<td>Dysosmia</td>
<td></td>
</tr>
<tr>
<td>Dysphonia</td>
<td></td>
</tr>
<tr>
<td>Dyspraxia (Speech)</td>
<td></td>
</tr>
<tr>
<td>Ear Infection</td>
<td></td>
</tr>
<tr>
<td>Ear Wax</td>
<td></td>
</tr>
<tr>
<td>Environmental Pollution</td>
<td></td>
</tr>
<tr>
<td>Gustation</td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
</tr>
<tr>
<td>Hearing Aids</td>
<td></td>
</tr>
<tr>
<td>Hearing Identification</td>
<td></td>
</tr>
<tr>
<td>Hoarseness</td>
<td></td>
</tr>
<tr>
<td>Hyperacusis</td>
<td></td>
</tr>
<tr>
<td>Hypogeusia</td>
<td></td>
</tr>
<tr>
<td>Hyposmia</td>
<td></td>
</tr>
<tr>
<td>Kallman's Syndrome</td>
<td></td>
</tr>
<tr>
<td>Labyrinthine Hydrops</td>
<td></td>
</tr>
<tr>
<td>Laryngeal Carcinoma</td>
<td></td>
</tr>
<tr>
<td>Laryngeal Nodules</td>
<td></td>
</tr>
<tr>
<td>Laryngeal Paralysis</td>
<td></td>
</tr>
<tr>
<td>Laryngectomy</td>
<td></td>
</tr>
<tr>
<td>Meniere's Disease</td>
<td></td>
</tr>
<tr>
<td>Middle Ear Infections</td>
<td></td>
</tr>
<tr>
<td>Misarticulation</td>
<td></td>
</tr>
<tr>
<td>Motion Sickness</td>
<td></td>
</tr>
<tr>
<td>Motor Speech Disorders</td>
<td></td>
</tr>
<tr>
<td>Newborn Hearing Screening</td>
<td></td>
</tr>
<tr>
<td>Noise-Induced Hearing Loss</td>
<td></td>
</tr>
<tr>
<td>Noise</td>
<td></td>
</tr>
<tr>
<td>Nonsyndromic Hereditary Hearing Impairment</td>
<td></td>
</tr>
<tr>
<td>Olfaction</td>
<td></td>
</tr>
<tr>
<td>Acoustic Neuroma</td>
<td>Dystonia</td>
</tr>
<tr>
<td>Alport Syndrome</td>
<td>Genetics</td>
</tr>
<tr>
<td>Alzheimer's Disease</td>
<td>Hearing Loss and Aging</td>
</tr>
<tr>
<td>Apraxia</td>
<td>Labyrinthitis</td>
</tr>
<tr>
<td>Attention Deficit Disorder</td>
<td>Landau Kleffner Syndrome</td>
</tr>
<tr>
<td>Autism</td>
<td>Language</td>
</tr>
<tr>
<td>Bacterial Meningitis</td>
<td>Language Development</td>
</tr>
<tr>
<td>Brain Tumor</td>
<td>Learning Disabilities</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>Meige's Syndrome (Facial Dystonia)</td>
</tr>
<tr>
<td>Cleft Lip and Palate</td>
<td>Neural Stimulation</td>
</tr>
<tr>
<td>CMV (Cytomegalovirus)</td>
<td>Neurofibromatosis (von Recklinghausen's Disease)</td>
</tr>
<tr>
<td>Communication (Disorders)</td>
<td>Otitis Media</td>
</tr>
<tr>
<td>Developmental Disorders</td>
<td>Presbycusis</td>
</tr>
<tr>
<td>Dysarthria</td>
<td>Ramsey Hunt Syndrome</td>
</tr>
<tr>
<td>Dyslexia</td>
<td>Reading Development</td>
</tr>
<tr>
<td>Dysphagia</td>
<td></td>
</tr>
<tr>
<td>Dystonia</td>
<td></td>
</tr>
<tr>
<td>Genetics</td>
<td></td>
</tr>
<tr>
<td>Hearing Loss and Aging</td>
<td></td>
</tr>
<tr>
<td>Language Development</td>
<td></td>
</tr>
<tr>
<td>Learning Disabilities</td>
<td></td>
</tr>
<tr>
<td>Meige's Syndrome (Facial Dystonia)</td>
<td></td>
</tr>
<tr>
<td>Neural Stimulation</td>
<td></td>
</tr>
<tr>
<td>Neurofibromatosis (von Recklinghausen's Disease)</td>
<td></td>
</tr>
<tr>
<td>Otitis Media</td>
<td></td>
</tr>
<tr>
<td>Presbycusis</td>
<td></td>
</tr>
<tr>
<td>Ramsey Hunt Syndrome</td>
<td></td>
</tr>
<tr>
<td>Reading Development</td>
<td></td>
</tr>
<tr>
<td>Reading Disorders</td>
<td>Spasmodic Dysphonia</td>
</tr>
<tr>
<td>Speech and Language Disorders</td>
<td>Speech</td>
</tr>
<tr>
<td>Speech</td>
<td>Speech and Language Disorders</td>
</tr>
<tr>
<td>Stroke</td>
<td>Sroke</td>
</tr>
<tr>
<td>Swallowing Disorders</td>
<td>Swallowing Disorders</td>
</tr>
<tr>
<td>Taste</td>
<td></td>
</tr>
<tr>
<td>Tongue</td>
<td></td>
</tr>
<tr>
<td>Tourette Syndrome</td>
<td></td>
</tr>
<tr>
<td>Trauma Research</td>
<td></td>
</tr>
<tr>
<td>Usher Syndrome</td>
<td></td>
</tr>
<tr>
<td>Vertigo</td>
<td></td>
</tr>
<tr>
<td>Vocal Cord Paralysis</td>
<td></td>
</tr>
<tr>
<td>Williams Syndrome</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX B
TIMELINE OF EVENTS

- OHCPL identifies need to improve quality of statistical information for constituents (Summer, 2001) and begins to plan for a review of materials and applies for evaluation set-aside funding.

- OHCPL successfully competes for set-aside Evaluation grant to evaluate and improve data available publicly (January, 2002).

- Meeting held with DER and EDSB to identify strategy and potential participants (Fall, 2001).

- Experts invited to participate in December 14, 2001 conference call (Fall, 2001).

- Literature searches conducted across medical and social science literature including approval of search strategies (Spring/Summer, 2002).

- Search results reviewed (Summer, 2002).

- Searches, sample strategies, review charge and currently used data mailed out (Summer, 2002).

- Individual extended telephone conference calls subject by subject (Summer, 2002).

- Individual experts submit written summaries and key literature and chapter items (Fall, 2002).

- Preliminary items prepared for Web launch (Fall, 2002).

- Descriptive report completed (Fall, 2002).

- Second level of statistical data and links launched (late Fall, 2002).
APPENDIX C
AD HOC COMMITTEE ON EPIDEMIOLOGY AND STATISTICS
COMMUNICATION

Richard L. Doty, Ph.D.
Professor and Director
Smell and Taste Center
University of Pennsylvania Medical Center

George A. Gates, M.D.
Virginia Merrill Bloedel Hearing Research Center
University of Washington

Bruce Tomblin, Ph.D.
Department of Speech Pathology and Audiology
University of Iowa

Coleen Boyle, Ph.D.
Associate Director for Science and Public Health
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Karen J. Cruickshanks, Ph.D.
Ophthalmology and Visual Sciences
Population and Health Sciences
University of Wisconsin-Madison

NIDCD Co-Chairs:

Marin P. Allen, Ph.D.
Communication Director and Chief, OHCPL

Robert Dobie, M.D.
Director, Division of Extramural Research

Howard Hoffman, M.S.
Chief, Epidemiology and Data Systems
APPENDIX D
SEARCH STRATEGIES BY CATEGORY

HEARING AND BALANCE SEARCHES


Decibel Information - (decibel or decibels) & (deafness[mh] OR "hearing impairment" OR "hearing disorders"[mh] OR hearing loss, noise induced[mh] OR occupational exposure[mh] OR occupational diseases[mh] OR environmental exposure[mh]) limits: Publication Date from 1997, English;
(decibel or decibels) & (deafness[mh] OR "hearing impairment" OR "hearing disorders")[mh] OR hearing loss, noise induced[mh] OR occupational exposure[mh] OR occupational diseases[mh] OR environmental exposure[mh]) limits: Publication Date from 1992, English, Reviews


Hyperacusis - "hyperacusis"[mh] & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English: No reviews available

labyrinthitis [mh] & (ep [sh] OR incidence [mh] OR prevalence [mh]) - limits Publication Date from 1992, English, Reviews

Meniere's Disease - meniere's disease [mh] & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English:
meniere's disease [mh] & (ep [sh] OR incidence [mh] OR prevalence [mh]) :: Publication Date from 1992, English, Reviews


Motion Sickness - "motion sickness"[MESH] & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English: No reviews available


Noise-Induced Hearing Loss - noise-induced hearing loss & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English:

((nonsyndromic & hereditary & hearing & loss) OR (deafness/ge [majr]) & deafness/ep [mh]) limits: Publication Date from 1992, English: Reviews


Otitis Media (see middle ear infections)


Ototoxic Drugs - ototoxic* AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English; ototoxic* AND (drug OR drugs) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review


Positional Vertigo - ("positional vertigo" OR "vertigo"[mh]) AND (ep[sh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English; ("positional vertigo" OR "vertigo"[mh]) AND (ep[sh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review


Prosthesis (Hearing) - ("ossicular prosthesis"[mh] OR (hearing AND (prosthes* OR implant OR implants)) AND (ep[sh] OR incidence[mh] OR prevalence[mh])) Limits: Publication Date from 1997, English;
("ossicular prosthesis"[mh] OR (hearing AND (prosthes* OR implant OR implants)) AND (ep[sh] OR incidence[mh] OR prevalence[mh])) Limits: Publication Date from 1992, English, Review


"Hearing Loss, Sensorineural"[MESH] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review

"Deafness, Sudden"[MESH] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review


Tactile Devices - ("ear protective devices"[mh] OR "hearing device*" OR "eye protective devices"[mh] OR "tactile device*") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English;
("ear protective devices"[mh] OR "hearing device*" OR "eye protective devices"[mh] OR "tactile device*") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review

Temporal Bone Bank - ("Temporal Bone"[MESH] OR "bone banks"[MESH]) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English;
("Temporal Bone"[MESH] OR "bone banks"[MESH]) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review

Tinnitus - tinnitus[mh] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English;

SMELL AND TASTE SEARCHES


Kallman's Syndrome - no articles or review available

Parosmia - parosmia AND (ep[sh] OR incidence[mh] OR prevalence[mh] OR "occupational exposure"[mh] OR "environmental exposure"[mh]) Limits: Publication Date from 1997, English;


Smell (Disorders) - ("Olfaction Disorders/epidemiology"[MESH] OR "smell"[mh]) AND (ep[sh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English;
("Olfaction Disorders/epidemiology"[MESH] OR "smell"[mh]) AND (ep[sh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review


Taste Disorders - "taste disorders"[MESH] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English;
"taste disorders"[MESH] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review


VOICE, SPEECH AND LANGUAGE SEARCHES


Apraxia - "Apraxias"[MESH] & (ep[sh] OR incidence[mh] OR prevalence[mh])


communications disorders [mh] OR deafness[mh] OR "hearing impairment" OR "hearing disorders"[mh] OR "sensation disorders"[mh]) - limits Publication Date from 1992, English, Reviews


Dysarthria - (dysarthria [mh]) & (ep[sh] OR incidence[mh] OR prevalence[mh]) - limits Publication Date from 1997, English;
(dysarthria [mh]) & (ep[sh] OR incidence[mh] OR prevalence[mh]) - limits Publication Date from 1992, English, Reviews


Dyslexia - (dyslexia [mh]) & (ep[sh] OR incidence[mh] OR prevalence[mh]) - limits Publication Date from 1997, English;
(dyslexia [mh]) & (ep[sh] OR incidence[mh] OR prevalence[mh]) - limits Publication Date from 1992, English, Reviews

Dysphagia - (dysphagia [mh]) & (ep[sh] OR incidence[mh] OR prevalence[mh]) AND (communications disorders [mh] OR deafness[mh] OR "hearing impairment" OR "hearing
disorders"[mh] OR "sensation disorders"[mh]) - limits Publication Date from 1997, English:


Laryngeal Carcinoma - laryngeal neoplasms/ep OR laryngeal neoplasms [majr] & (incidence [mh] OR prevalence [mh]) - limits: Publication Date from 1997, English
laryngeal neoplasms/ep OR laryngeal neoplasms [majr] & (incidence [mh] OR prevalence [mh]). ]): Publication Date from 1992, English, Reviews

Laryngeal Paralysis - vocal cord paralysis [mh] & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English: No reviews available

Laryngectomy - ("laryngectomy/statistics and numerical data"[MESH] OR "laryngectomy/utilization"[MESH]) limits: Publication Date from 1997, English: No reviews available

Laryngitis - "laryngitis"[MESH] & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English:
"laryngitis"[MESH] & (ep [sh] OR incidence [mh] OR prevalence [mh]) ]): Publication Date from 1992, English, Reviews

Motor Speech Disorders - ("Movement Disorders"[MESH] AND "speech disorders"[MESH]) & (ep [sh] OR incidence [mh] OR prevalence [mh]) limits: Publication Date from 1997, English:
("Movement Disorders"[MESH] AND "speech disorders"[MESH]) & (ep [sh] OR incidence [mh] OR prevalence [mh])]: Publication Date from 1992, English, Reviews


**Reading Disorders** - ("Dyslexia"[MESH] OR "reading disorder*") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]): Limits: Publication Date from 1997, English;


**Spasmodic Dysphonia** - "spasmodic dysphonia" AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]): Limits: Publication Date from 1997, English


**Speech** - "speech"[MESH] AND (disorder* OR "communication disorders"[mh]) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]): Limits: Publication Date from 1997, English;
"speech"[MESH] AND (disorder* OR "communication disorders"[mh]) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]): Limits: Publication Date from 1992, English, Review
Speech and Language Disorders - ("speech disorders"[MESH] OR "language disorders"[MESH]) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh])
Limits: Publication Date from 1997, English;
("speech disorders"[MESH] OR "language disorders"[MESH]) AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review

Stroke - "Cerebrovascular Accident"[MESH] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) AND ("communications disorders"[mh] OR deafness[mh] OR "hearing impairment" OR "sensation disorders"[mh])
Limits: Publication Date from 1997, English;

Stuttering - stuttering[mh] AND (ep[sh] OR incidence[mh] OR prevalence[mh])
Limits: Publication Date from 1997, English;

Swallowing Disorders - (degultition[mh] OR "swallowing disorder*") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh])
Limits: Publication Date from 1997, English;

Tactile Devices - ("ear protective devices"[mh] OR "hearing device*" OR "eye protective devices"[mh] OR "tactile device*") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh])
Limits: Publication Date from 1997, English;
("ear protective devices"[mh] OR "hearing device*" OR "eye protective devices"[mh] OR "tactile device*") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review

Throat Disorders - (pharynx[mh] OR throat) AND disorder* AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh])
Limits: Publication Date from 1997, English;
Pharynx[mh] OR throat AND disorder* AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review

Tourette Syndrome - "tourette syndrome"[MESH] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh] OR "occupational exposure"[mh] OR "environmental exposure"[mh])
Limits: Publication Date from 1997, English;

Trauma Research - "Wounds and Injuries"[MESH] AND (research[mh] OR "trauma research") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh] OR "occupational exposure"[mh] OR "environmental exposure"[mh]) AND (ear OR nose OR throat OR eye OR eyes OR communication OR deafness or "hearing impairment")
Limits: Publication Date from 1997, English;
("Wounds and Injuries"[MESH] OR trauma) AND research[mh] AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh] OR "occupational exposure"[mh] OR "environmental exposure"[mh]) Limits: Publication Date from

Velocardiofacial Syndrome - (velocardiofacial OR "velocardiofacial syndrome") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1997, English;
(velocardiofacial OR "velocardiofacial syndrome") AND (epidemiology[mh] OR incidence[mh] OR prevalence[mh]) Limits: Publication Date from 1992, English, Review


Vocal Tremor - (vocal OR "vocal cords"[mh]) AND tremor AND (epidemiology OR incidence OR prevalence) Limits: Publication Date from 1997, English;
((vocal OR "vocal cords"[mh]) AND tremor) Limits: Publication Date from 1992, English, Review


APPENDIX E
CURRENT PUBLICLY USED STATISTICS -- DRAFT-DRAFT-
DRAFT

HEARING

1. An estimated 28 million people in the United States are deaf or hard of hearing.
National Institute on Deafness and Other Communications Disorders (NIDCD). National
Strategic Research Plan: Hearing and Hearing Impairment. Bethesda, MD: HHS, NIH,
1996.

2. Some 1,465,000 individuals aged 3 years or older are deaf in both ears.

3. Estimates based on emerging data indicate that 2 to 3 per 1,000 live births have
congenital hearing loss.
Reports of prevalence from State programs. [Texas, 3.14 per 1,000] Albright, K. and
(102):142-146, 1998; [Hawaii, 1.4 per 1,000] Mason, J.A. and Herrmann, K.R. Universal
Infant Hearing Screening by Automated Auditory Brainstem Response Measurement.
Pediatrics (101):221-228, 1998; [New Jersey, 2.9 per 1,000] Barsky-Firske, L. and Sun,

4. 2 to 3 per 1,000 live births with congenital hearing loss does not include children who
are born with normal hearing but have late-onset or progressive hearing loss. Hearing
loss often is sufficient to prevent the spontaneous development of spoken language.
Yoshinaga-Itano, C. and Apuzzo, M.L. Identification of hearing loss after 18 months is

5. More than 50 percent of childhood hearing impairments are believed to be of genetic
origin.

6. Minimal hearing loss also is an important factor in school success and psychological
development.
Bess, F.H.; Dodd-Murphy, J.; and Parker, R.A. Children with minimal sensorineural
hearing loss: Prevalence, educational performance and functional status. Ear and Hearing

7. Estimates for the average age of diagnosis of hearing loss in infants and children
range from 14 months to around 3 years.
American Academy of Pediatrics. Newborns and infant hearing loss: detection and


Another form of hearing loss is Meniere's disease, which causes bilateral, often fluctuating, hearing loss in 20 to 40 percent of cases, usually in conjunction with balance disorder and tinnitus. NIDCD. Because You Asked About Meniere's Disease. Washington, DC: HHS, 1-7.


Approximately 10 million persons in the United States have permanent, irreversible hearing loss from noise or trauma. NIDCD. Fact Sheet on Noise-Induced Hearing Loss. Washington, DC: HHS, 1998.
15. Thirty million people are estimated to be exposed to injurious levels of noise each
day. Noise-induced hearing loss (NIHL) is the most common occupational disease
and the second most self-reported occupational illness or injury.
National Institute for Occupational Safety and Health (NIOSH). Fact Sheet: Work-

16. In industry-specific studies, 44 percent of carpenters and 48 percent of plumbers
reported they had a perceived hearing loss.
Lusk, S.L.; Kerr, M.J.; and Kauffrman, S.A. Use of hearing protection and perceptions of
noise exposure and hearing loss among construction workers. American Industrial

17. Ninety percent of coal miners are estimated to have a hearing impairment by age 52
years, and 70 percent of male metal and nonmetal miners will experience a hearing
impairment by age 60 years.
Franks, J.R. Analysis of Audiograms for a Large Cohort of Noise-Exposed Miners.
Cincinnati, OH: HHS, Centers for Disease Control and Prevention, NIOSH, Division of
Biomedical and Behavioral Science, 1996.
Mine Safety and Health Administration. Health Standards for Occupational Noise
Exposure in Coal, Metal, and Nonmetal Mines: Proposed Rule. Federal Register 61:243-
66347-66397, December 17, 1196.

18. Data indicate that people are losing hearing earlier in life and that men are more
frequently affected in the 35-60-year-old age group.
Wallhagen, M.I.; Strawbridge, W.J.; Cohen, R.D.; et al. An Increasing prevalence of
hearing impairment and associated risk factors over three decades of the Alameda County

19. The average reading level for deaf persons aged 18 years is estimated at the fourth
grade.
Kelly, L.P. Using silent motion pictures to teach complex syntax to adult deaf readers.

20. Presbycusis, the loss of hearing associated with aging, affects about 30 percent of
adults who are aged 65 years and older.
Gates, G.A.; Cooper, Jr., J.C.; Kannel, W.B.; et al. Hearing in the elderly: The

21. About half of the population over age 75 years has a significant hearing loss.
Cruickshanks, K.J.; Wiley, T.L.; Tweed, T.S.; et al. Prevalence of hearing loss in older
adults in Beaver Dam, Wisconsin: The Epidemiology of Hearing Loss Study. American

22. Only about one-fourth of those who could benefit from a hearing aid actually use one.

23. More than 8 percent of the population aged 70 years and older report both hearing and vision impairment.

24. Data indicate that tinnitus affects almost 15 percent of adults aged 45 years and older.

25. Three out of four children experience otitis media by the time they are 3 years old.

26. Approximately 70,000 people worldwide have received implants. In the United States, some 21,000 people have implants; about half of these are adults and half are children.

27. Hearing impairments occur in about 20 percent of individuals with Type 1 Waardenburg Syndrome.

28. About 50 percent of persons with Waardenburg Syndrome Type 2 have a hearing impairment or are deaf.

29. More than half of the estimated 16,000 deaf-blind people in the United States are believed to have Usher Syndrome.

30. Together, Usher Syndrome 1 and Usher Syndrome 2 account for approximately 10 percent of all cases of children who are born deaf.

31. At least 12 million Americans have tinnitus. Of these, at least 1 million experience it so severely that it interferes with their daily activities.
American Tinnitus Association. Portland, OR.

32. 15 percent of those with sudden sensorineural hearing loss experience a hearing loss that gets worse over time.
Approximately 4,000 new cases of sudden sensorineural hearing loss occur each year in the United States.

Sudden sensorineural hearing loss happens most often to people between the ages of 30 and 60 years of age.

Hearing loss affects approximately 17 in 1,000 children under age 18.

Approximately 314 in 1,000 people over age 65 have hearing loss.

Balance

1. An estimated 6.2 million Americans reported chronic problems of dizziness and/or balance.

2. Nine percent of the estimated 6.2 million Americans who reported chronic problems of dizziness and/or balance are 65 years and older.

3. Unilateral vestibular schwannomas account for approximately 8 percent of all tumors inside the skull.

4. One out of every 100,000 individuals per year develops a vestibular schwannoma.

5. Approximately, there are 615,000 individuals with diagnosed Meniere's disease in the United States and 45,500 newly diagnosed cases each year.
SMELL

1. More than 200,000 people visit a physician each year for help with smell disorders or related problems.

TASTE

1. More than 200,000 people visit a physician for help with taste disorders or related problems.

VOICE

1. Laryngeal papillomatosis affects infants and small children as well as adults.
   Between 60 and 80 percent of cases occur in children, usually before the age of three.

2. The first signs of spasmodic dysphonia are found most often in individuals between 30 and 50 years of age. More women appear to be affected by spasmodic dysphonia than are men.

SPEECH

1. It is estimated that over three million Americans stutter.

2. Stuttering affects individuals of all ages but occurs most frequently in young children between the ages of 2 and 6 who are developing language.

3. Boys are three times more likely to stutter than girls.

4. It is estimated that less than 1 percent of adults stutter.

5. Cleft palate is the fourth most common birth defect affecting approximately one of every 700 live births.
6. Velocardiofacial Syndrome occurs in approximately 5 to 8 percent of children born with a cleft palate.

7. It is estimated that over 130,000 individuals in the United States have Velocardiofacial Syndrome.

LANGUAGE

1. It is estimated that approximately 80,000 individuals acquire aphasia each year.

2. About 1 million persons in the United States currently have aphasia.

3. Current estimates suggest that approximately 400,000 individuals in the United States have autism.

4. Approximately 75 percent are of low intelligence while 10 percent may demonstrate high intelligence in specific areas such as math.

5. Landau-Kleffner syndrome (LKS) is the gradual or sudden loss of the ability to understand and use spoken language. LKS occurs most frequently in normally developing children who are between 3 and 7 years of age.

6. More than 160 cases have been reported.
APPENDIX F
STATISTICS AND HUMAN COMMUNICATION

Below are the contents of the new section of the NIDCD Web page on statistics and human communication.

Statistics are available on:
- Hearing
- Smell
- Taste
- Voice, Speech, and Language

Basics. The branch of medical science that investigates all the factors that determine the presence or absence of disease is called epidemiology. Epidemiologists study the incidence, or the number of new cases of a disease in a population over a period of time, and prevalence, the number of existing cases of a disease in a population at a given time. Cost-of-illness or burden-of-disease are two measures of the economic and social impact of diseases in a population.

Challenges. Statistical and epidemiological data on diseases and disorders of human communication are limited.
- Much of the data, as they deal with human sensory experience, are based on self-report rather than on objective data. This might mean that individual interpretation of the question or self-estimates of, for example, hearing loss may be an under- or overrepresentation.
- Some of the data are based upon household survey data where one individual will describe the other members of the household, rather than having, for example, an audiometric test of each individual. Many estimates are based upon comparisons across time that may have variability in the definitions of or what is included in clustered terms like hearing loss or speech disorder.
- Another difficulty is that the scientists may not agree on the best way to measure a particular disorder.

Statistics on Hearing

- Hearing loss is greater in men.
- Almost 12 percent of men who are 65 to 74 years of age are affected by tinnitus. Tinnitus is identified more frequently in white individuals and the prevalence of tinnitus is almost twice as frequent in the South as in the Northeast.

Summary Report

Hearing loss is a common problem in modern society due to the combined effects of noise, aging, disease, and heredity. Hearing is a complex sense involving both the sensitivity of the ear as well as the ability to understand speech. Determining the prevalence of hearing loss depends on the type and degree of the loss, the area(s) of abnormality in the auditory system (middle ear, inner ear, brain, e.g.), noise exposure, and age. Mild losses may not be noticed and even moderate losses may not impose a problem for people with excellent perceptual abilities and good coping skills. Hearing loss may be defined by self-report, by report of friends and family, and by hearing testing. Formal audiometric testing is the gold standard for diagnosis and treatment monitoring. Testing may be done at any age.

For prevalence of hearing loss estimates, all these metrics are of value and each provides a part of the complex picture of the burden of hearing loss on society. Self-report of hearing loss is important because it
is relatively simple to determine and provides a global assessment of the impact of the problem on the individual. Formal audiometry provides relatively precise information displayed by frequency and hearing level. A convenient summary of the audiogram is the pure-tone average (PTA) of the cardinal speech frequencies (500, 1000, 2000, 3000 Hz). As the PTA increases, the hearing ability decreases. Normal hearing for speech is observed for people with PTAs of 25 dB or less. At a PTA of around 40 dB in both ears, most people are functionally handicapped and benefit from amplification. Severe to profound losses range from PTAs of 75 dB and greater. At this level, hearing aids provide limited benefit and consideration of cochlear implants is generally given.

An accurate assessment of hearing includes laterality (one or both ears affected), degree of threshold loss (PTA), and best ability to understand speech (either with hearing aids or loud presentation levels). Other factors include the rapidity of loss onset/progression (people often adapt to slowly progressive losses more than sudden losses), associated symptoms such as tinnitus, hyperacusis and recruitment (intolerance to loud sounds), and type of treatment options (surgery, hearing aids, aural rehabilitation, speech reading, assistive listening devices).

Hearing loss may be estimated in terms of societal burden, effect on the person, and treatment needs. For purposes of estimating the societal burden of hearing loss, age-specific rates of self (or family) report are essential. For estimating the impact of hearing loss on the person, a PTA of 25 dB generally requires adaptive listening strategies. Active treatment is generally required at PTA of 40 dB or greater in both ears.

Deafness is generally applied to people with severe bilateral loss (PTA > 75 dB). Because modern cochlear implants are helpful to people with severe losses of relatively short duration (<10 years), duration of hearing loss has become another important factor in describing hearing loss.

Books and articles


Franks JR. *Analysis of Audiograms for a Large Cohort of Noise-Exposed Miners*. Cincinnati, OH: HHS, Centers for Disease Control and Prevention, NIOSH, Division of Biomedical and Behavioral Science, 1996.


Reports of prevalence from state programs.


Statistics on Smell.

- 1-2% of the North American population below the age of 65 years experience smell loss to a significant degree.

According to estimates based on reported research, 1-2% of the North American population below the age of 65 years, experience smell loss to a significant degree. Smell lost is much greater in older populations, with nearly half of individuals between the ages of 65 to 80 years seemingly experiencing smell loss and nearly three-quarters of those over the age of 80 years experiencing such loss.

Note: These are the best estimates available from studies using actual smell tests. Survey's asking about smell ability without the administration of tests are likely to underestimate smell loss, since many individuals are not aware of their dysfunction unless it is marked. This phenomenon has been noted not only in "normal" populations, but in individuals diagnosed with disorders associated with smell disorders such as Alzheimer's disease and idiopathic Parkinson's disease.

Summary Report

Overview of Smell Disorders

The vast majority of patients presenting to physicians with chemosensory (smell and taste) disturbances, including "taste disturbances," exhibit olfactory dysfunction. As with the case of the taste system, the olfactory system plays a significant role in eating, as most food and beverage flavors are, in fact, dependent upon this system. Such common "tastes" as chocolate, coffee, strawberry, apple, peach, pizza, steak sauce, and chicken actually reflect olfactory-mediated sensations that require the integrity of CN I. Molecules are released and propelled upwards towards the olfactory receptors via the nasal pharynx during mastication and deglutition (Burdach & Doty, 1987).

The olfactory receptors, unlike the receptors of most sensory systems, are directly exposed to the outside environment, save their protection by a thin layer of mucus, making them relatively susceptible to damage from such exogenous agents as viruses, bacteria, pollutants, and airborne toxins. Moreover, since the axons of the olfactory receptor cells extend through the foramina of the cribiform plate to synapse within the olfactory bulb of the central nervous system (CNS), they are extremely vulnerable to shearing and tearing from movement of the brain relative to the cranium. This occurs, for example, in accelerative/decelerative head trauma injuries, even in the absence of fractures, contusions or other objective evidence of trauma (Doty et al., 1997b). The direct route of the olfactory receptor cells from the nasal cavity to the brain makes the olfactory receptors a major conduit for the movement of environmental agents into the brain, in effect bypassing elements of the blood brain barrier. Among agents known to use this route as a means of entrance into the CNS are such viruses as polio virus (e.g., Bodian & Howe, 1940), rabies virus (e.g., Dean et al., 1963), Herpes simplex virus (e.g., Dinn, 1980), and human immunodeficiency virus (e.g., Brody et al., 1991).

In light of the olfactory anatomy, it is perhaps not surprising the most common causes of permanent smell loss are (a) upper respiratory infections, such as the common cold, (b) head trauma or rapid head acceleration or deceleration, and (c) rhinosinusitis. Although the data are limited, these three causes account for the majority of patients who present to physicians with chemosensory disturbance (Duncan & Seiden, 1995). The percent of patients presenting to specialized centers with these etiologies vary slightly from institution to institution, depending upon their referral bases or referral criteria. In general, about a quarter of patients in such populations have smell loss secondary to URI's, about 20% secondary to head trauma, and 15% secondary to rhinosinusitis (Deems et al., 1991). Other less common causes of smell loss include chronic alcoholism (Shear et al., 1992), epilepsy Kohler et al., 2001), Kallmann's syndrome (Hudson et al., 1994), Korsakoff's psychosis (Mair et al., pseudohypoparathyroidism (Doty et al., 1997a)
and a number of common neurological disorders, including multiple sclerosis (Doty et al., 1997b, 1999), schizophrenia (Moberg et al., 1999), Huntington's disease (Blysma et al., 1998; Moberg & Doty, 1997), Alzheimer's disease (Doty et al., 1987; Murphy et al., 1999), and idiopathic Parkinsonism (Doty et al., 1988). In the case of multiple sclerosis, the smell dysfunction is directly related to the number of plaques within the subtemporal and orbitofrontal cortices, waxing and waning in relation to plaque activity (Doty et al., 1997, 1999). In the case of AD and PD, smell loss appears to be the first clinical sign of the disorder, occurring long before the cardinal signs of the syndromes. In the case of PD, smell loss is unrelated to anti-parkinson medication use and is more common (~90%) than tremor (~85%) (Doty et al., 1992). Smell testing can aid in differential diagnosis, since some neurological diseases, often misdiagnosed as Alzheimer's disease or idiopathic Parkinson's disease, are unaccompanied by meaningful olfactory loss (e.g., major affective disorder (McCaffrey et al., 2000), progressive supranuclear palsy (Doty et al., 1993), essential tremor (Busenbark et al., 1992) and MPTP-induced parkinsonism (Doty et al., 1992).

It is important to note that smell testing of patients at risk for AD may be the best predictor of who later will be clinically diagnosed with AD (Murphy et al., 1988). For example, in an epidemiological study of 1,604 non-demented community-dwelling senior citizens 65 years of age or older, scores on a 12-item odor identification test were a better predictor than scores on a global neuropsychological test of cognitive decline over a subsequent 2-year time period (Graves et al., 1999). Persons who were anosmic and possessed at least one APOE-4 allele had 4.9 times the risk of having cognitive decline than normosmic persons not possessing this allele (i.e., an odds ratio of 4.9). This is in contrast to the 1.23 times greater risk for cognitive decline in normosmic individuals possessing at least one such APOE allele. When the data were stratified by sex, women who were anosmic and possessed at least one APOE-4 allele had an odds ratio of 9.71, compared to an odds ratio of 1.90 for women who were normosmic and possessed at least one allele. The corresponding odds ratios for men were 3.18 and 0.67, respectively.

Exposure to a number of toxic agents can induce smell loss. Olfactory loss can occur as a result of exposure to toxins in general air pollution and in workplace settings, where litigation becomes a consideration. In addition to directly damaging the olfactory neuroepithelium, some toxins may produce damage indirectly by inducing upper respiratory inflammatory responses or infections that, in turn, induce such damage. The best scientific documentation of toxic exposure in humans is for acrylates, methacrylates, and cadmium, with the former being typically being reversible after removal from the workplace and the latter inducing, in unregulated settings, longer-lasting or permanent effects. Schwartz et al. (1989) tested the olfactory function of 731 workers at a chemical plant that manufactured acrylates and methacrylates. A nested case-control study designed to assess the cumulative effects of exposure on olfactory function found crude exposure odds ratios (95% confidence intervals) of 2.0 (1.1, 3.8) for all workers and 6.0 (1.7, 21.5) for workers who had never smoked cigarettes. Logistic regression analysis, adjusting for multiple confounders, found exposure odds ratios of 2.8 (1.1, 7.0) and 13.5 (2.1, 87.6) in these same respective groups and a dose-response relationship between the olfactory and cumulative exposure scores. Decreased odds ratios were associated with increasing duration since last exposure to the chemicals, implying some degree of reversibility. This seems less likely for cadmium, although similarly sophisticated studies have not been performed. Yin-Zeng et al. (1985) reported that 28% of individuals who had worked five years or more in a cadmium-refining plant claimed having anosmia, although quantitative testing was not performed. The average concentration of airborne cadmium was said to be relatively low (between 0.004 and 0.187 mg/m³), but still slightly above the current OSHA permissible exposure limit of 0.005 mg/m³. Rose et al. (1992) found moderate to severe hyposmia, but not anosmia, to n-butanol in 55 workers exposed for an average of 12 years to cadmium fumes, a phenomenon correlated with body burden of cadmium, as measured by urinalysis. Rydzewski et al. (1998) compared the olfactory thresholds of 73 workers involved in the production of cadmium-nickel batteries to that of 43 nonexposed, age- and smoking-matched controls. Anosmia or hyposmia was found in 45.2% of the cadmium-nickel exposed group, compared to only 4.6% of the controls.

**Books and Articles**


References for Editorial Comment:


Study Citations:


Statistics on Taste

- Approximately 25% of Americans are nontasters, 50%, medium tasters, and 25%, "supertasters".

Summary Report

Taste buds, located mainly on the lingual surface, palate, and oropharynx, are primarily responsible for mediating sweet, sour, bitter, salty, and metallic sensations. The physiologic role of the taste system is multifold and includes (a) triggering ingestive and digestive reflex systems that alter the secretion of oral,
gastrić, pancreatic, and intestinal juices (Schiffman, 1997; Giduck et al., 1987), (b) reinforcing the ingestive process by enhancing the feelings of pleasure and satiety (Warwick et al., 1993), and (c) enabling the determination of the quality of sampled foodstuffs and distinguishing nutrients (which usually taste "good", e.g., sweet) from potential toxins (which usually taste "bad", e.g., bitter) (McLaughlin and Margolskee, 1994). Although rarely appreciated, taste dysfunction can alter food choices and patterns of consumption, producing weight loss, malnutrition, and in some cases impaired immunity and even death. Apparent increased sensitivity and aversion to bitter-tasting substances on the part of the pregnant mother during the first trimester presumably reflects the need to detect and avoid bitter tasting poisons and teratogens during this critical phase of fetal development (Duffy et al., 1998). Similarly, increased preferences for salty and bitter tasting substances during the remainder of pregnancy likely encourages the eating of a varied diet and the ingestion of much needed electrolytes to expand fluid volume. In someone who is hypertensive or diabetic, taste loss can lead to a dangerous tendency to over-compensate for the loss by adding additional salt or sugar to the food.

Whole mouth taste dysfunction is rare, largely because of the redundant innervation of the taste buds (some buds are innervated by CN VII, some by CN IX, and some by CN X). Nonetheless, such function decreases with aging to some degree, can be influenced by central tumors and lesions (e.g., ischemic infarcts secondary to stroke), and is altered adversely by a number of medications. Regional taste deficits, which are much more common, often go undetected, reflecting, in part, the aforementioned redundant neural innervation. Regional deficits can be quite marked. For example, in one study none of 12 elderly persons detected NaCl presented to small regions of the tongue, unlike 12 younger individuals who exhibited no problems with such detection (Matsuda & Doty, 1995). Importantly, taste sensitivity, as measured by detection thresholds, is directly related to the number of taste papillae and taste buds stimulated, implying that some taste disorders are conceivably accounted for by changes in the peripheral lingual anatomy (Doty et al., 2001; Miller et al., 2002).

The most debilitating taste disorders are those in which a persistent, often chronic, bad taste is present, such as a bitter or salty taste. The causes of such dysgeusias are poorly understood, although they usually appear later in life. In addition to dental and oral health considerations (e.g., the presence of dissimilar metals in oral appliances, purulent discharge from infected teeth or gums), viruses, physical damage to one or more taste nerves, and various medicines are a cause of some dysgeusias. Among offending medicines are lipid reducing agents, antibiotics, and antihypertensive, anxiolytic, and antidepressant drugs. Fortunately, most dysgeusias spontaneously resolve over time (Deems et al., 1996).

Formal determinations of the prevalence of taste dysfunction in the general population are not available, although a large literature exists on differential sensitivity to bitter tasting agents, such as phenothiocarbamide (PTC) and 6-n-propylthiouracil (PROP). Variations in sensitivity seem to vary among genetically disparate populations, although the methods of determining such differential sensitivity are varied. Based upon supra threshold scaling, some investigators have divided individuals into nontasters, medium tasters, and supertasters. In the case of PROP, Bartoshuk et al. (1998) estimate that approximately 25% of Americans are nontasters, 50%, medium tasters, and 25%, supertasters. Such tasting ability correlates with the number of fungiform papillae, as well as sensitivity to some other agents (e.g., NaCl, sucrose), begging the question as to whether sensitivity to PROP is a simple reflection of the number of taste buds. However, the relationship between such a classification scheme and clinical pathology, if any, has not been elucidated. Interestingly, PTC sensitivity is reportedly higher in some patient populations (e.g., tuberculosis), suggesting a linkage with susceptibility to some diseases (Freire-Maia & Queiroz-Salgado, 1997).

Taste problems are much less prevalent than olfactory ones. In patients presenting to taste and smell centers with chemosensory dysfunction, the vast majority exhibit no taste demonstrable dysfunction at all (Deems et al., 1991; Goodspeed et al., 1986), even though most exhibit bilateral deficits in olfactory functioning. However, most such studies have employed whole-mouth taste tests.

### Books and Articles


Statistics on Voice, Speech, and Language

The functions, skills and abilities of voice, speech, and language are related. Some dictionaries and textbooks use the terms almost interchangeably. But, for scientists and medical professionals, it is important to distinguish among them.

On this page:
- Voice
- Speech
- Language

Books and Articles

Voice

- Approximately 7.5 million people in the United States have trouble using their voices.

Voice Summary Report
Voice (or vocalization) is the sound produced by humans and other vertebrates using the lungs and the vocal folds in the larynx, or voice box. Voice is not always produced as speech, however. Infants babble and coo, animals bark, moo, whinny, growl, and meow, and adult humans laugh, sing, and cry. Voice is generated by airflow from the lungs as the vocal folds are brought close together. When air is pushed past the vocal folds with sufficient pressure, the vocal folds vibrate. If the vocal folds in the larynx did not vibrate normally, speech could only be produced as a whisper. Your voice is as unique as your fingerprint. It helps define your personality, mood, and health.

Approximately 7.5 million people in the United States have trouble using their voices. Disorders of the voice involve problems with pitch, loudness, and quality. Pitch is the highness or lowness of a sound based on the frequency of the sound waves. Loudness is the perceived volume (or amplitude) of the sound, while
quality refers to the character or distinctive attributes of a sound. Many people who have normal speaking skills have great difficulty communicating when their vocal apparatus fails. This can occur if the nerves controlling the larynx are impaired because of an accident, a surgical procedure, a viral infection, or cancer.

**Speech**

- The prevalence of speech sound disorder in young children is 8 to 9%.

**Speech Summary Report**

Humans express thoughts, feelings, and ideas orally to one another through a series of complex movements that alter and mold the basic tone created by voice into specific, decodable sounds. Speech is produced by precisely coordinated muscle actions in the head, neck, chest, and abdomen. Speech development is a gradual process that requires years of practice. During this process, a child learns how to regulate these muscles to produce understandable speech.

However, by the first grade, roughly five percent of children have noticeable speech disorders; the majority of these speech disorders have no known cause. One category of speech disorder is fluency disorder, or stuttering, which is characterized by a disruption in the flow of speech. It includes repetitions of speech sounds, hesitations before and during speaking, and the prolonged emphasis of speech sounds. More than 15 million individuals in the world stutter, most of whom began stuttering at a very early age. The majority of speech sound disorders in the preschool years occur in children who are developing normally in all other areas. Speech disorders also may occur in children who have developmental disabilities.

Children with specific speech sound disorders, which has also been termed articulation disorder or phonological disorder, have clinically significant difficulties producing the speech sounds of their language expected for their age. The extent of these patterns of errors will affect the intelligibility of their speech to some degree and in some cases rendering the speech unintelligible to those unfamiliar with the child. Two recent publications provide summaries of prevalence estimates of this condition (Law et al. 2000; Shriberg, Tomblin, and McSweeny 1999). All these estimates have focused on children in the early school years and the prevalence estimates range from 2% among the oldest children who were 8 years old, to 24.6% among the youngest who were 5 years old. Much of this variability can be attributed to different diagnostic standards. The median prevalence estimate across these studies falls in the range of 8-9%. These studies all showed a greater rate of impairment in boys than girls with male to female ratios ranging from 1.5 to 2.4.

Speech sound disorders have been shown to occur with SLI, particularly among children referred for clinical services. Risk factors for speech sound disorders consist of family histories of speech sound disorder (Lewis, Ekelman, and Aram 1989) and chronic otitis media (Shriberg LD et al. 2000).

**Language**

- Between 6 and 8 million people in the United States have some form of language impairment.

**Language Summary Report**

Language is the expression of human communication through which knowledge, belief, and behavior can be experienced, explained, and shared. This sharing is based on systematic, conventionally used signs, sounds, gestures, or marks that convey understood meanings within a group or community. Recent research identifies "windows of opportunity" for acquiring language--written, spoken, or signed--that exist within the first few years of life.

Between 6 and 8 million individuals in the United States have some form of language impairment. Disorders of language affect children and adults differently. For children who do not use language normally from birth, or who acquire an impairment during childhood, language may not be fully developed or acquired. Many children who are deaf in the United States use a natural sign language known as American Sign Language (ASL). ASL shares an underlying organization with spoken language and has its own syntax and grammar. Many adults acquire disorders of language because of stroke, head injury, dementia, or brain tumors. Language disorders also are found in adults who have failed to develop normal language
skills because of mental retardation, autism, hearing impairment, or other congenital or acquired disorders of brain development.

Primary or Specific Language Impairments (SLI) are diagnosed in children who have clinically significant impairments in their development of spoken language in the absence of sensory or neurodevelopmental disorders. Spoken language in this case includes the ability to understand words, sentences, and connected speech as well as the ability to express messages using appropriate vocabulary, grammar, and discourse. Standards for the diagnosis of SLI vary and therefore prevalence estimates across studies vary accordingly. Variation in prevalence also appears to be affected by a pattern of recovery for many children during the early preschool years. Much greater stability over age is seen in children during the school years. Law et al. (2000) have reviewed studies estimating prevalence of SLI during the preschool and early school years. The typical range of prevalence estimates was between 2% and 8% with an overall median prevalence of 5.95%. Most studies reported a greater prevalence of SLI in boys than girls. The male to female sex ratios varied from .98:1 to 2.30:1. Risk factors for SLI have been found to concentrate on family factors (Tomblin, Smith, and Zhang 1997; Tomblin 1992). Limited parental education, and parental history of speech, language, and/or learning problems have been found to be associated with elevated rates of SLI (Bishop 2001; Bishop 2001; Stromswold 1998). In contrast, breast feeding has been shown to serve as a protective factor even in the context of parental education. Reading impairments have been widely shown to be strongly associated with SLI (Catts et al. 2001; Catts 1993).

Books and Articles

Top
APPENDIX G
COMBINED HEALTH INFORMATION DATABASE (CHID)

The Combined Health Information Database (CHID) is a reference tool for searching thousands of journal articles and patient education materials containing information about different health topics.

CHID is a cooperative effort among different Federal agencies. These agencies combined their information files into one database to create a single source of health information. CHID has been available to the public since 1985. Currently, CHID covers 16 topic areas. The user can search either individual topics or the entire database. The topics are:

- AIDS, STD, and TB Education (AD)
- Alzheimer's Disease (AZ)
- Arthritis and Musculoskeletal and Skin Diseases (AR)
- Cancer Prevention and Control (CP)
- Complementary and Alternative Medicine (AM)
- Deafness and Communication Disorders (DC)
- Diabetes (DM)
- Digestive Diseases (DD)
- Epilepsy Education and Prevention (EP)
- Health Promotion and Education (HE)
- Kidney and Urologic Diseases (KU)
- Maternal and Child Health (MC)
- Medical Genetics and Rare Disorders (MG)
- Oral Health (OH)
- Prenatal Smoking Cessation (PS)
- Weight Control (WC).

New topics will be added over time. Each topic is updated quarterly.
After a search term was entered into the databases, the number of citations was counted. If the number of citations was less than 70, the reviewer would read through each title and abstract to determine if they met the inclusion criteria. Any questions were presented to a second reviewer for final determination. If the resulting number of citations for an individual search term was greater than 70, then a second level search was implemented. In these instances, the original search term was paired with more than 15 additional terms in order to focus the search more narrowly. For example, the term "stuttering" may result in the identification of over 1,000 publications. In order to narrow this search, the word "stuttering" was then paired with terms such as "incidence", "prevalence", and "epidemiology". These paired terms would result in a much more focused set of citations for review. Social science publications were identified for more than 40 of the more than 100 categories searched. In total, this literature search resulted in the identification of over 140 publications. NIDCD staff in epidemiology and communication reviewed all abstracts from both of the searches to determine the appropriateness, representativeness and completeness of the searches.